

"DOING THE SAME PUZZLE OVER AND OVER AGAIN": A QUALITATIVE ANALYSIS OF FEELING STUCK IN GRIEF

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A thesis submitted in partial fulfilment of the requirements of the
University of East London for the degree of Professional
Doctorate in Counselling Psychology

July 2013

Word Count: 28,665

Abstract

This research aimed to examine the meanings and constructions underlying narratives on feeling stuck in the grieving process and the interplay between grief experience and the internally and externally sourced expectations about the nature of grief. Four participants who self-referred to a National Bereavement support charity and reported feeling stuck in grief were interviewed and the resultant transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

Four Master Themes emerged from the analysis: Eclipsed by the deceased; The power in powerlessness; The double-edged sword of coping behaviours and Living in Purgatory. The results reveal new insights on the significance and consequences of living with unresolved dilemmas of grieving, namely being stuck in a vicious cycle of fear and avoidance and feeling a sense of impending doom, loneliness and stagnancy.

Findings support a meaning reconstruction approach to grief therapy and highlight the negative implications of holding a time-limited, stage-based conceptualisation of grief. Suggestions for service providers are made, including the potential for using targeted cognitive-behavioral grief interventions that can help to reduce dissonance and address an over dependence on avoidance and polarised thinking.

Acknowledgements

Thank you to the participants who volunteered their time to be interviewed during a very difficult time in their lives. I feel privileged to have met you all and to be representing your stories within my research. Thank you also to Cruse Bereavement Care, specifically my local branch whose support was invaluable in the recruitment of participants.

I would also like to thank my fantastic supervisor Dr. Jane Lawrence who has tirelessly read every page of this thesis, providing me with guidance and encouragement along the journey. I also want to thank Dr. David Kaposi who went above and beyond the call of duty to ensure I had supervision during the critical analysis phase. Both supervisors have been instrumental in helping me to reflect on the profound connection I felt with the participants and their stories, and to capture this passion for my subject effectively in the write up.

And finally, I would like to thank my parents. Without your financial and emotional support and belief in me, none of this would have been possible.

Contents

	PG
ABSTRACT	II
ACKNOWLEDGEMENTS	III
CONTENTS	1 - 4
LIST OF FIGURES	5
ABBREVIATIONS	5
INTRODUCTION	6 – 8
CHAPTER 1 – LITERATURE REVIEW	9 -33
1.1 INTRODUCTION	9 – 10
1.2 DEFINITIONS	10
1.3 THE ROLE OF CULTURE IN GRIEF	10 – 12
1.4 THEORIES OF GRIEF – A HISTORICAL PERSPECTIVE	13 -16
1.4.1 PSYCHOANALYTIC	13
1.4.2 STAGE THEORIES	13 – 16
1.5 CHALLENGING COMMON ASSUMPTIONS ABOUT ‘NORMAL’ GRIEF	16 – 17
1.6 NEW EMERGING PERSPECTIVES ON GRIEF	17 – 20
1.6.1 DUAL PROCESS MODEL OF COPING WITH BEREAVEMENT	18
1.6.2 MEANING RECONSTRUCTION	19
1.6.3 INTEGRATED MODEL OF MEANING MAKING	19 – 20
1.7 DEVELOPMENTS IN GRIEF RESEARCH	21 – 24
1.8 A RESURGENCE OF THE MEDICAL MODEL: CATEGORISING GRIEF AND THE ‘FUNDAMENTAL PARADOX’ IN GRIEF LITERATURE	24 – 28

1.8.1 PROLONGED GRIEF DISORDER	24 – 28
1.9 UNDERSTANDING THE EXPERIENCE OF GRIEF: THE CHALLENGE FACING THERAPISTS AND RESEARCH	28 – 31
1.10 IMPLICATIONS FOR THEORY AND PRACTICE	31 – 32
1.11 RESEARCH QUESTIONS	32 – 33
CHAPTER 2 - METHODOLOGY	34 – 53
2.1 RESEARCH PARADIGM – WHY HERMENEUTIC PHENOMENOLOGY?	34 – 35
2.2 RESEARCH METHODOLOGY – WHY IPA?	35 – 38
2.3 EMBEDDING QUALITY INTO THE DESIGN	38 – 40
2.4 ETHICAL CONSIDERATIONS	40 - 42
2.5 RESEARCH DESIGN FRAMEWORK	42 - 52
2.5.1 SAMPLING AND RECRUITMENT	42 – 45
2.5.2 CONTEXT	45 – 46
2.5.3 INTRODUCTION TO PARTICIPANTS	46
2.5.4 DATA COLLECTION	47 – 48
2.5.5 DATA ANALYSIS	48 - 52
I) READING, RE-READING AND INITIAL COMMENTING	48 – 50
II) DEVELOPING EMERGENT THEMES	50 - 52
2.6 CONCLUDING COMMENTS	53
CHAPTER 3 - ANALYSIS	54 – 92
3.1 OVERVIEW	54
3.2 INTRODUCTION TO THEMES	54 - 55
3.3 MASTER THEME 1: ECLIPSED BY THE DECEASED	56 – 64
3.3.1 IDEALISING THE DECEASED	56 – 59

3.3.2 'THEY WERE PART OF ME': LOSS AS AMPUTATION	59 – 60
3.3.3 FEAR OF LETTING GO	61 – 64
3.4 MASTER THEME 2: THE POWER IN POWERLESSNESS	64 – 73
3.4.1 FEELING OUT OF CONTROL	65 - 66
3.4.2 FEELING LET DOWN BY OTHERS	67 – 69
3.4.3 FEELING OBLIGED TO 'GET ON WITH IT'	70 – 73
3.5 MASTER THEME 3: THE DOUBLE EDGED SWORD OF COPING BEHAVIOURS	73 – 83
3.5.1 'LOCKED INSIDE': NEGATING EMOTIONS	73 – 76
3.5.2 'LIKE WORZEL GUMMAGE': AVOIDANCE AS RELIEF	76 – 80
3.5.3 PRIORITISING OTHERS OVER SELF	80 – 83
3.6 MASTER THEME 4: LIVING IN PURGATORY	83 – 90
3.6.1 IMPENDING DOOM	83 – 86
3.6.2 LONELINESS	86 – 87
3.6.3 'DOING THE SAME PUZZLE OVER AND OVER AGAIN': STAGNANT	88 – 90
3.7 ANALYSIS SUMMARY	91 – 92
CHAPTER 4 - DISCUSSION	93 – 116
4.1 OVERVIEW	93 – 94
4.2 UNDERSTANDING THE EMERGENT THEMES IN THE CONTEXT OF EXISTING GRIEF LITERATURE	94 – 104
4.2.1 THE UNRESOLVED DILEMMAS OF GRIEVING	95 – 100
I) THE ZERO SUM GAME	96 – 98
II) THE POWERFUL POWERLESS	98 – 100
4.2.2 STUCK IN A VICIOUS CYCLE	100 – 102

4.2.3 THE PURGATORIAL CONSEQUENCES OF LIVING IN AMBIVALENCE	102 - 104
4.3 SUMMARY OF FINDINGS	104 - 106
4.4 CLINICAL IMPLICATIONS	106 - 110
4.5 REFLEXIVITY	110 - 114
4.6 CRITIQUE OF THE RESEARCH	114 - 116
4.7 SUGGESTIONS FOR FUTURE DIRECTIONS IN GRIEF RESEARCH	116
CHAPTER 5 - CONCLUSION	117 - 119
REFERENCES	120 - 135
APPENDICES	136 - 178
APPENDIX I ETHICS APPROVAL – UEL, CRUSE	136 - 138
APPENDIX II RECRUITING LEAFLET - VOLUNTEERS	139
APPENDIX III RECRUITING LEAFLET - PARTICIPANTS	140
APPENDIX IV INTERVIEW SCHEDULE	141
APPENDIX V INFORMATION SHEET FOR PARTICIPANTS	142
APPENDIX VI INFORMED CONSENT	143
APPENDIX VII DEBRIEFING LEAFLET	144
APPENDIX VIII PICTORIAL REPRESENTATIONS OF THEMES	145 -147
APPENDIX IX ILLUSTRATIVE QUOTES FOR THEMES	148 - 154
APPENDIX X INTERVIEW TRANSCRIPT (MABEL)	155 - 178

List of Figures

- Figure 1. Rescaled results from nonlinear regression analyses of an empirical test of stage theory of grief (Source: Maciejewski et al, 2007). *Page 14*
- Figure 2. The Dual Process Model of coping with bereavement (Source: Stroebe & Schut, 2001). *Page 18*

Abbreviations

APA	American Psychiatric Association
CG	Complicated Grief
CGT	Complicated Grief Treatment
DPM	Dual Process Model
DSM-V	Diagnostic Statistical Manual of Mental Disorders
GAD	Generalised Anxiety Disorder
IPA	Interpretative Phenomenological Analysis
MDD	Major Depressive Disorder
PGD	Prolonged Grief Disorder
PTSD	Post Traumatic Stress Disorder
UEL	University of East London

Introduction

I have worked for Cruse Bereavement Care, the National charity supporting bereaved individuals, for over 4 years and heard many clients reporting feeling stuck in their grieving process. However, when researching this widely cited phenomenon within the grief literature, I was unable to find the richness and depth of the devastation, pain and loneliness that are inherent in my client's experiences. At the same time, changes to the Diagnostic Statistical Manual of Mental Disorders (DSM-V) were being proposed and debated: the proposed inclusion of Prolonged Grief Disorder (Prigerson, VanderWerker & Maciejewski, 2008), and the proposed removal of the bereavement exclusion from the diagnosis of Major Depressive Disorder (Lamb, Pies & Zisook, 2010). These changes have elicited significant criticism for their potential to pathologise normal grief responses to bereavement and their contribution to the widely held stage-based construction of grief: that we should grieve according to cultural norms and tight deadlines.

Research that explores aspects of grief and improves our understanding is of particular relevance to the discipline of Counselling Psychology. In a survey of 729 psychiatric outpatients, over half were found to have experienced a significant loss, and about a third met the criteria for moderate to severe complicated grief (Piper, Ogrodniczuk, Azim & Weideman, 2001). The population of clients who seek and receive therapeutic interventions from Counselling Psychologists is therefore likely to include a proportion of individuals who are feeling stuck in their grieving process. Growing evidence

suggests that grief therapy is most effective for the 11% to 15% (Prigerson et al, 2008; Shear et al, 2011) of bereaved individuals who are stuck in a chronic state of mourning (Currier, Neimeyer & Berman, 2008; Neimeyer & Currier, 2009; Worden, 2009). Furthermore, the effectiveness increases for this group when the therapeutic interventions are targeted (Matthews & Marwit, 2004), informed by contemporary theories of grief (Shear et al, 2005) and are combined with a focus on the therapeutic relationship (Hardy et al, 2001). The requirement for a flexible approach, grounded in psychological theory, to therapeutic interventions for this group of clients arguably means that Counselling Psychologists are particularly well-positioned to work effectively with this group of clients. As Clarkson (1998, p10) asserts, Counselling Psychology seems “uniquely placed, and can, without too much historical baggage be the approach to evaluate and implement theories which are used as tools, as metaphors [] rather than as laws set in tablets of stone, unresponsive to changing conditions, unaware of the interrelatedness of all our explanatory theoretical nets”.

I was inspired to take a hermeneutic phenomenological approach to exploring the lived experience of feeling stuck in grief. By using this inductive approach and the client's language of 'feeling stuck', it was hoped that subjective experience would be given a voice as opposed to a label of complicated or prolonged grief. The research examines the meanings and constructions underlying narratives on feeling stuck in the grieving process and the interplay between grief experience and the internally and externally sourced expectations about grieving.

This study is aligned to several contemporary directions in grief research, including the lived experience (Davies, 2004), adaptation to loss (Rothaupt & Becker, 2007; Worden, 2009) and the social and cultural aspects of meaning-making (Park 2010; Stroebe, Hansson, Schut & Stroebe, 2008). The centrality of the role of meaning-making in the adjustment to traumatic events (Park & Folkman, 1997) and of the importance of continuing bonds (Klass, Silverman & Nickman, 1996) locates this study within a burgeoning body of research.

Three key research findings in this study comprise a distinctive contribution to Counselling Psychology and bereavement research. Firstly, the significant dilemma of unresolved internal conflicts in the experience of individuals feeling stuck in grief is highlighted. Secondly, the distressing consequences of living in ambivalence as a result of the unresolved conflicts are highlighted. And thirdly, this research positions the service providers' conceptualisation of grief as paramount to the efficacy of future therapeutic interventions, specifically the risk of not effectively addressing internal conflicts in grief clients by working from a stage model of grief.

Chapter One

Literature Review

"I not only live each endless day in grief, but live each day thinking about living each day in grief." C.S. Lewis, (1961)

1.1 Introduction

This critical review of bereavement research begins with an overview of the cultural context that has shaped Western¹ grief theories and the cultural diversity identified in mourning rituals that has inspired a fresh perspective on the norms of grieving. The traditional psychoanalytic and stage-based theories are summarised, followed by a critique of the common assumptions held about 'normal' grief and an introduction to the contemporary developments in grief theory and research methodology which reflect a shift in approach towards meaning reconstruction and the uniqueness of grief experience. Contradictory to this position, however, is a resurgence of the medicalisation and categorisation of grief, manifest in the proposal by some researchers (Prigerson, VanderWerker & Maciejewski, 2008; Shear et al, 2011) for a prolonged/complicated grief diagnosis to be included in DSM-V. Conflict between attempts to delineate 'normal' grief and the widely held belief that all grief experience is unique represents a fundamental paradox in the grief literature (Breen & O'Connor, 2007). The implications for therapists and researchers of the pervasive tendency to conceptualise grief as a stage-based and time-limited response to loss are explored, and the existing literature on the phenomenon of feeling stuck in grief within this construction

¹ The term 'Western society' in this study reflects the definition offered by Harris (2010, p 241) and refers "to a philosophical stance that is deemed as 'Western-oriented', but not limited to a geographic location or particular culture or ethnic identification"

of grief is reviewed. The chapter concludes with a summary of the research questions addressed in this qualitative study.

1.2 Definitions

Despite grief being understood to be a universal experience, the definition is not universally agreed upon in bereavement literature. Operational definitions of grief vary from broad: '*highly unique, personal response to loss*' (Lang & Caplan, 1993) to the more specific: '*primarily emotional reaction to the loss of a loved one through death*'. (Stroebe, Hansson, Schut & Stroebe, 2008, p5). For the purposes of this research, Howarth's (2011, p4) comprehensive definition of grief will be utilised: '*the various emotional, physiological, cognitive and behavioural reactions to the loss of a loved one to death*'.

1.3 The role of culture in grief

Although the overall effect of bereavement has been found to be the same across cultures (Alford & Catlin, 1993), the nature of that effect and the way grief is experienced depends on unique cultural characteristics (Mystakidou et al, 2004). Individuals are prepared, through cultural traditions, to respond to the death of a loved one in a certain way and these notions guide the actual response to bereavement (Alford & Catlin, 1993). Western cultural traditions played an important role in shaping traditional grief theories where grief work was thought to lead to a relinquishment of attachment with the

deceased (Lalande & Bonanno, 2006) and to recovery following bereavement (Rosenblatt, 2007).

However, these notions are largely irrelevant for some cultures and research on these cultural mourning customs has expanded knowledge on what is adaptive mourning. For example the Maoris, the indigenous population of New Zealand, grieve collectively and don't acknowledge the idea of recovery as a redefinition of the individual self (Rosenblatt, 2007). Maintaining bonds with the deceased is overtly encouraged through ritualised ceremonies in many cultures including China (Lalande & Bonanno, 2006), Japan (Stroebe, Gergen, Gergen & Stroebe, 1992) and in Egypt (Rothaupt & Becker, 2007), but is forbidden in the Hopi tribe of Arizona as contact with the deceased is viewed as polluting (Stroebe et al, 1992). Lalande & Bonanno (2006) found that continuing bonds with the deceased is only likely to be an adaptive response to grief if it is culturally accepted and the bereaved are supported by their community.

Diverse mourning rituals across cultures reflect the extent to which death and grief are prepared for within communities and the different ways they are perceived. For example, the Greek language defines the word 'end' as both a termination and purpose, which leads to an understanding of death as the final goal in life and as a departure on a journey. Certain cultural mourning customs are still carried out in parts of Greece, which were specifically created hundreds of years ago in order to prevent complicated grief reactions (Loukatos, 1978, cited in Mystakidow et al, 2004). These include the Cretan customs of wearing black clothes, men growing a beard,

the wife and sister cutting their hair as a symbol of strength for the deceased and the holding of memorial services on the 3rd, 9th, 40th days after the funeral and then after 6 months, 9 months and annually thereafter (Mystakidow et al, (2004).

Walter (2006) argues that the concept of 'complicated grief' is a social construction, and a reflection of the cultural norms in Western society. These norms, which are widely known yet never explicitly stated, impact the bereaved profoundly by governing the support offered and public policies following a death (Harris, 2010). Grief norms are proposed to operate along several dimensions: What should be done with the emotions of grief, to what extent should mourners spend time with the dead, how long should grief last, how legitimate is the loss, how should grief be manifest and is there any stigma surrounding the death? (Harris, 2010; Walter, 2006). Culture has been found to shape, limit, define and create grieving, but Rosenblatt (2008) argues that you need to go beyond a description of an individual's culture. An understanding of the fit between how someone is grieving and what their culture asks of bereaved people is required. Walter (2006) maintains that the concept of 'complicated' grief is not only rooted in the mourner's psyche, but also in the concern from society to reduce their own inconvenience and worry, and to replace the ensuing chaos and guilt with order and predictability.

1.4 Theories of grief – a historical perspective

1.4.1 Psychoanalytic

The classic psychoanalytic view of grief, drawn primarily from Freud's (1917) seminal paper 'Mourning and Melancholia', was a dominant model in 20th century bereavement literature. It emphasises the importance of 'the work of mourning', which should continue until the bereaved individual has sufficiently 'worked through' their loss and freed themselves from their intense attachment from the deceased. Only recently has this model been challenged and the concepts such as grief work criticised for being too broad and lacking in clarity (Stroebe & Schut, 2001).

1.4.2 Stage Theory

During the second half of the 20th Century, stage theories of grief began to emerge. Bowlby (1969) applied his influential attachment theory to the process of grief, which he perceived as a struggle between the opposing forces of activated attachment behaviour and the reality of the loved one's absence. Bowlby & Parkes (1970) present a four-stage process of grieving: (1) Numbness, shock and denial with a sense of unreality, (2) Yearning and protest. (3) Despair, disorganisation, hopelessness, low mood, (4) Re-organisation, involving letting go of the attachment and investing in the future. The model was the first to provide a rationale for searching and anger, and it remains influential in grief research because it provides a framework for understanding individual differences in response to loss (Wortman & Boerner, 2007). Kubler-Ross (1969) adapted Bowlby & Parkes'

(1970) stage model to propose a five-stage model of the responses of terminally ill patients: (1) Denial, (2) Anger, (3) Bargaining, (4) Depression, (5) Acceptance. Kubler-Ross' (1969) stage theory has since been widely accepted and generalised to a wide variety of losses (Wortman & Boerner, 2007) and continues to be taught to, and accepted by, medical professionals as the model of 'normal' grief (Kilcrease, 2008).

Despite being entrenched in grief literature and the training manuals of medical professionals, attempts to find empirical proof for stages have only been made in the last few years. Maciejewski, Zhang, Block, & Prigerson (2007) aimed to empirically determine 'normal' grief through the analysis of data generated from the Yale Bereavement Study, in order to improve the identification and treatment for those labelled with 'abnormal' bereavement adjustment. Maciejewski et al (2007) interviewed 233 participants at 3 intervals over a 24 month post-bereavement period, focusing on the frequency that participants experienced the five stages of grief proposed by Jacobs (1993): Disbelief, yearning, anger, depression and acceptance. The researchers assert that the data provides an exact fit to the hypothesised sequence of Jacob's (1993) stages of grief, thereby providing the first empirical support for the stage model of grief (see Figure 1).

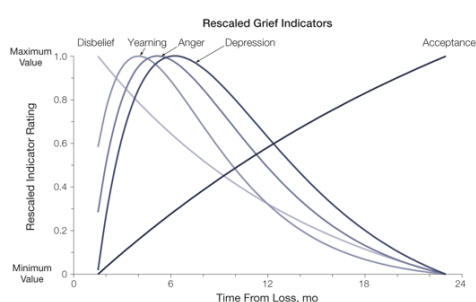


Figure 1. Rescaled results from nonlinear regression analyses of an empirical test of stage theory of grief (Source: Maciejewski et al, 2007)

However, serious doubt has been cast on the validity of this research (Kilcrease, 2008), primarily for its selective recruitment of participants. 40% of participants were excluded either through design, thought not to be experiencing 'normal' grief, or choice, participants who opted out due to feeling fine, or providing no response (Silver & Wortman, 2007). It can also be argued that although the five stages in Maciejewski et al's (2007) results (see Figure 1) can be seen to peak in a sequence, each element occurs simultaneously throughout the 24-month period, which is specifically *not* representative of stages (Roy-Byrne & Shear, 2007).

A new wave of grief theory has been identified in the last decade, which reflects a changing zeitgeist about the role of loss in human experience and these theories are sceptical about stage theory where an emotional trajectory is purported to lead from psychological disequilibrium to readjustment (Neimeyer, 2001). It is argued that stage theory doesn't allow for variability in response, and places the grieving individual in a passive role, focusing primarily on emotional response whilst ignoring cognitions and behaviours (Wortman & Boerner, 2007). Others assert that stage theory is an artificial construct that has the potential to pathologise those who don't follow the defined stages (Kilcrease, 2008). As a grief theory, stage theory offers little in explanatory value, about how people might cope with the loss, why they might experience varying degrees of distress at different times and how they can adjust to a life without their loved one (Bonanno, 2007). It is increasingly accepted in contemporary bereavement literature that, although a stage model of grief persists in the general population (Costa, Hall &

Stewart, 2007), a mistaken belief in this conceptualisation of grief can lead to ineffective support, unhelpful responses from medical professionals and can leave bereaved individuals feeling that they are not coping appropriately (Silver & Wortman, 2007).

1.5 Challenging common assumptions about ‘normal’ grief

Wortman & Boerner (2007) identify some common assumptions about coping following the loss of a loved one, held by medical professionals and laypersons, which have little or no supporting empirical evidence but are often implicit in stage theories. Their findings highlight the rigidity of the common conceptualisation of ‘normal’ grief, which fails to consider the unique context of every loss. For example, there is an expectation that bereaved individuals will show significant distress after a major loss, the absence of which would be indicative of maladaptive coping. Maladaptive, in this context, refers to processes employed to manage environmental demands (Lazarus & Folkman, 1984), where adaptive coping is defined as “the effectiveness of coping in improving the adaptational outcome” (Lazarus, 1993, p237). However, in an analysis of research, the proportion of participants who experienced little grief reaction was between 26% and 78% in various studies, with no evidence of delayed grief (Wortman & Boerner, 2007). Far from maladaptive coping, Stroebe, Hanson & Stroebe (1993) found that a lack of distress can be explained by early adjustment or relief that the deceased is no longer suffering.

Another assumption, derived from the psychoanalytic view of grief (Freud, 1917) is that once the process of 'working through' the loss is completed and the ties to the deceased have been relinquished, recovery will be achieved with a return to pre-bereavement levels of psychological distress. Firstly, research has found that continuing bonds with the deceased is not pathological but normal, and although not uniformly adaptive, it can be beneficial (Boerner & Heckhausen, 2003; Klass, Silverman & Nickman, 1996). Secondly, recovery in bereavement is no longer an appropriate term as it implies a closure that has been found not to occur. Wortman & Boerner (2007) refer to a growing consensus that bereaved individuals may never return to their pre-loss state, as major losses are thought to produce lasting changes in a person's character (Weiss, 1993).

1.6 New emerging theoretical perspectives on grief

In their review of Western bereavement theories, Rothaupt & Becker (2007) highlight a recent shift in focus from the healing of pathology in bereavement to an approach which facilitates the adaptation to loss. Similarly, a shift in bereavement research has been recognised towards a non-positivistic approach where the focus is increasingly on the lived experience and meaning-making in grief (Davies, 2004). Neimeyer (2001) identifies several commonalities in the emerging bereavement theories: a focus on cognitive processes, emotional consequences and the role of families and the wider social context, appreciate the potential for post traumatic growth, and a shift away from psychoanalytic thinking where detachment from the deceased is deemed essential.

1.6.1 Dual Process Model of coping with bereavement

The effectiveness of coping is a focus for bereavement researchers as it is assumed to have an impact on adaptation to bereavement, where improvements in coping effectiveness are linked with reductions in suffering and in mental and physical health difficulties (Stroebe & Schut, 2010). Stroebe & Schut's (2001) Dual Process Model (DPM) of coping with bereavement expands on the grief work hypothesis, with its psychoanalytic origins, asserting that grief work and sharing with others, although important, are not sufficient for adaptive coping.

The DPM model suggests that the loss of a loved one involves both loss-oriented coping – resolving aspects of the loss, *and* restoration-oriented coping - mastering challenges in everyday life that may have changed. Stroebe & Schut (2001) argue that it is the regulatory process of oscillation between loss-oriented and restoration-oriented coping (illustrated in Figure 2) that is the key to adaptive coping. Each mode of coping has costs attached to them, so by alternating between the two, the costs are minimised.

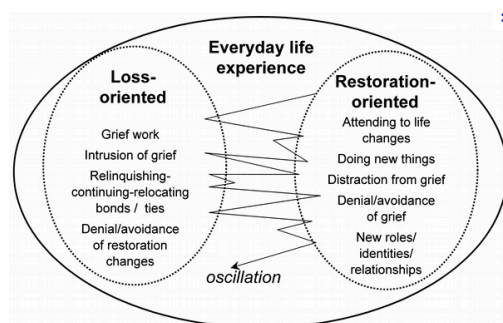


Figure 2 The Dual Process Model of coping with bereavement (Source: Stroebe & Schut, 2001)

1.6.2 Meaning Reconstruction

The role of meaning-making when dealing with and recovering from highly stressful experiences is widely accepted to be central (Park, Edmondson, Fenster and Blank, 2008). In their conceptualisation of meaning reconstruction, Gillies & Neimeyer (2006) suggest that the search for meaning occurs when the loss of a loved one is inconsistent with their pre-loss meanings held. The model proposes three meaning-making activities: sense making, benefit-finding and identity change which can help the bereaved individual construct new post-loss meanings. Within this model, *Sense-making* is viewed as central to the experience of grief whereby bereaved persons question, find, and make sense of their bereavement. *Benefit-finding* or the search for renewed purpose, describes the process of building new meaning structures incorporating the traumatic experience, assessing the value of an event on one's life more globally and reinvesting in a new future. *Identity change* refers to a reconstruction of self in response to a loss, including a greater sense of life's fragility with changes to resilience, independence, and confidence.

1.6.3 Integrated Model of Meaning-making

Despite convergence in the meaning-making literature pertaining to the centrality of meaning in traumatic events, there are pronounced inconsistencies regarding the widely held assumptions that over time people search for and find meaning, and that finding meaning is critically important for adjustment to these events (Park 2010). The concept of *meaning* has

been described as 'nebulous' (Stroebe & Schut, 2001) due to the rarity of agreement on terminology amongst researchers and theorists. With regard to definitions, meaning in the context of coping has many, including: a general life orientation, personal significance, causality and an outcome (Park & Blumberg, 2002).

Frustrated by the disparity between research findings, Park & Folkman (1997; Park 2010) developed an integrated model of meaning-making which proposes that an individual's global beliefs and goals, from which they derive purpose in life, form their global meaning system. When faced with a stressful life event, individuals appraise the situation and assign some form of meaning to it, and the extent to which this appraised meaning is discrepant with their global beliefs and goals determines the level of distress experienced. Most meaning-making theories generally converge on the notion that confrontation with severe stressors shatters one's global 'world assumptions' (Janoff-Bulman, 1992) or meaning systems which initiates meaning-making or cognitive processing to rebuild those meaning systems (Park et al, 2008). Meaning-making efforts attempt to reduce this discrepancy by either assimilation (changes in situational meaning) or accommodation (changes in global meaning) and are linked with improved adjustment.

Park & Folkman's (1997) model has succeeded in integrating diverse conceptual definitions and Park (2010) challenges researchers in this field to take a broader view of the ways that meaning is involved in the coping process and to be more explicit about the conceptual model underlying their studies.

1.7 Developments in grief research methodology

The most recent edition of the Handbook of bereavement research and practice (Stroebe, Hansson, Schut & Stroebe, 2008) continues to take a predominantly positivist approach, emphasising empirical studies and the effectiveness of increasingly sophisticated grief scales. Qualitative approaches to bereavement research seem to be valued for the potential to generate theory and as a way to ensure content validity for quantitative measures (Neimeyer, Hogan, Laurie, 2008), which is suggestive of a positivist/post-positivist approach. This position is also evident in Parkes' (1995) review of ethical criteria for bereavement research and Stroebe, Stroebe & Schut's, (2003) review of methodological issues in bereavement research where concepts usually associated with empirical research such as variables, control groups and validity are used in reference to assessing qualitative research design. Although Stroebe et al's (2003) review reflects a rise in popularity of the 'alternative' qualitative paradigm, both reviews highlight the enduring legacy of the positivist tradition in bereavement research. Within this environment, there is a risk in focusing on qualitative research that remains compatible with criteria of traditional quantitative studies, as it may lead to the isolation and rejection of more radical perspectives and methodologies (Yardley, 2000).

Two methods of data collection dominate bereavement research: large scale surveys and in-depth interviews (Stroebe et al, 2003). Recommendations to combine them in research projects include the bringing together of the strengths of each method (Morgan, 1998) and the overcoming of the

disadvantages inherent in both approaches (Stroebe et al, 2003). Dimond, Caserta & Lund's (1994) research is an example of such a design where they employed a preliminary quantitative survey to guide the data collection for 10 in-depth interviews about depression in bereaved spouses. Triangulation, whereby researchers choose to gather data from different sources or analyse data using more than one method, is understood to be a respected and beneficial way of achieving a rounded understanding of a complex topic such as grief (Yardley, 2000). Grounded theory (e.g. Nadeau, 1998; Rosenblatt & Wallace, 2005) offers the bereavement researcher the potential to integrate newly generated theory from qualitative data with that of quantitative survey data. Glaser (2003) asserts that Grounded theory is complementary to both paradigms, as it has the ability to provide a conceptual overview of the phenomenon that includes grounded interpretation, explanations, impacts and underlying causes.

A small number of researchers have recently introduced a phenomenological approach to bereavement research by conducting IPA studies (Golsworthy & Coyle, 2001; Robson, 2002; Begley & Quayle, 2007; Reilly, Huws, Hastings & Vaughan, 2008). Despite only being conceptualized in the mid 1990s, IPA research is argued to have already assumed a position as a dominant qualitative research methodology (Willig, 2008; Hefferon & Gil-Rodriguez, 2011), particularly in Health Psychology (Smith, 2010). The benefits that IPA offers researchers exploring illness experience: championing the individual's subjective report, recognition of the constructed nature of illness and understanding the meanings of their bodily

experiences (Brocki & Wearden, 2006), can equally benefit contemporary bereavement research.

Reilly et al (2008) chose to use IPA in their exploration into the experiences of mothers who have lost a child with intellectual disabilities. Based on Yardley's (2000) four guiding principles for quality in qualitative research (transparency and coherence, commitment and rigour, impact and importance, sensitivity to context), Reilly et al's (2008) research represents a high quality IPA study. The *transparency and coherence* are the most salient qualities, including the study's consistency with the underlying principles of IPA and reflexivity of the primary researcher's influence on the themes. They remain *sensitive to context* through their commitment to idiographic principles and by grounding their interpretations in the transcripts. The research demonstrates *commitment and rigour*, through the quality of the interview and thoroughness of the analysis, and *impact and importance* by providing new insight on the complexity of post-bereavement requirements for this group of mothers, including the shared need to maintain a role within the world of intellectual disability.

In their recent evaluation of the rise in popularity of IPA, Hefferon & Gil-Rodriguez (2011) identify that a failure to develop the analysis to a sufficient interpretative level will result in research that doesn't represent good IPA. An example of such research seems to be Begley & Quayle's (2007) exploration of the lived experience of adults bereaved by suicide. Their purely phenomenological position is inconsistent with the hermeneutic guiding principle of IPA, where the researcher is implicated in facilitating and making

sense of how a phenomenon appears to a participant (Smith et al, 2009). This results in a descriptive account, lacking in *coherence and transparency*, which fails to have *impact or importance* by giving little further insight into the nature, meaning and origin of the phenomenon.

1.8 A resurgence of the medical model: Categorising grief and the ‘fundamental paradox’ in grief literature

Given the unique and complex qualities of grief, many researchers are hesitant to distinguish ‘normal’ grief from ‘complicated’ grief, as it is dependent on cultural norms and expectations around the duration of symptoms and intensity (Stroebe, Hansson, Schut & Stroebe, 2008). Even the use of the term ‘complicated grief’ (CG) remains unresolved and has not escaped recent debate. However, Prigerson, VanderWerker & Maciejewski (2008) are among a selection of researchers who have championed the delineation of complicated or Prolonged grief disorder (PGD) from that of ‘normal’ grief and have proposed a set of PGD criteria for inclusion in the Fifth Edition of the Diagnostic Statistical Manual of Mental Disorders (DSM-V).

1.8.1 Prolonged grief disorder (previously known as Complicated Grief)

Prigerson et al (2008) chose the term PGD as they feel ‘complicated’ – defined as difficult to analyse, understand and explain – doesn’t represent the clarity they have provided in defining the features of PGD. The different terms are used interchangeably in the literature with little apparent

consensus, but for the purposes of this research, I shall use Prigerson et al's (2008, p166) conceptualisation of PGD, defined as 'a persistently elevated set of symptoms of grief identified in bereaved individuals with significant difficulties adjusting to the loss'.

Prigerson (2004) argues that by 6 months post-loss, the majority of bereaved people (80%-90%) reach a sense of acceptance, are able to engage in productive work, see the potential for future satisfying relationships and can enjoy leisure activities. Researchers assert this leaves between 11% (Prigerson et al, 2008) and 15% (Shear et al, 2011) bereaved individuals 'stuck' in a chronic state of mourning, a painful and debilitating reaction to bereavement that has been empirically distinguished from bereavement related depression and anxiety (Lichtenthal, Currier, Neimeyer, Keesee, 2010). Prigerson et al (2008) propose four criteria for a PGD diagnosis which is distinct from 'normal' grief, major depressive disorder (MDD), generalised anxiety disorder (GAD) and Post traumatic stress disorder (PTSD):

- A. At least one of the following three symptoms must be experienced by the bereaved individual: (1) intrusive thoughts related to the deceased, (2) intense pangs of separation distress (3) distressingly strong yearnings for the deceased.
- B. The bereaved individual must experience 5 of the following 9 symptoms daily or to a disruptive degree: (1) Confusion about one's role in life, diminished sense of self, (2) difficulty accepting the loss, (3) avoidance of reminders of the realities of the loss, (4) inability to trust others, (5) bitterness or anger related to the loss, (6) difficulty moving on with life, (7) numbness, (8) feeling that life is unfulfilling, empty and meaningless, (9) feeling stunned, dazed or shocked.
- C. Duration of at least 6 months since the onset of separation distress
- D. Cause clinically significant distress or impairment in social or occupational functioning.

Risk factors for PGD (or CG) are divided into three categories: the first is psychological vulnerability (history of mood disorders, insecure attachment styles, childhood abuse), the second is the circumstances of the death (violent, unexpected), and the third is the context in which the death occurs (insufficient social support, financial hardship) (Shear, Boelen & Neimeyer, 2011). Clinicians and researchers who support the inclusion of PGD in the DSM-V as a distinct mental illness (Prigerson et al, 2008; Shear et al, 2011) believe that it constitutes a clinically significant behavioural or psychological syndrome associated with present distress or disability, and therefore requires diagnosis and treatment.

The proposed categorisation of PGD in the Diagnostic and Statistical Manual of mental disorders - V (DSM V) is one of the most controversial issues in contemporary bereavement research (Stroebe et al, 2008). The categorisation of PGD is not the only grief-related controversy surrounding the DSM-V, as the American Psychiatric Association (APA) mood disorder work group is proposing to eliminate the bereavement exclusion from the criteria for classification of major depressive disorder (MDD) (Fox & Jones, 2013). Removal of the bereavement exclusion will facilitate the diagnosis of MDD in grieving individuals from 2 weeks post loss, if they satisfy the diagnostic criteria of 5 symptoms for 2 weeks (Wakefield & First, 2012). The proposal has been inspired primarily by research (Zisook & Kendler, 2007; Zisook, Shear & Kendler, 2007) that found that bereavement and depression have similar symptomology and both respond to antidepressant medication. This evidence contradicts Clayton's (1974) research cited to implement the bereavement exclusion in DSM-III and has been challenged by

phenomenological research. Pies (2009) argues that whereas depressed people tend to feel socially exiled, have a morbid preoccupation with 'me' and have a sense of permanence, bereaved people are able to feel an intimate connection with those around them, have an outward focus and generally believe that their sorrow is temporary. The removal of the bereavement exclusion from the diagnosis of MDD has been criticised for its potential to pathologise normal grief responses, but is supported by those who see bereavement as any other life stressor that can lead to the development of depression (Fox & Jones, 2013).

It is understood that the categorisation of 'normal' and 'abnormal' grief emerged following Lindemann's (1944, cited in Walter, 2006) seminal article, which was the first to use psychiatric terminology with reference to grief. These attempts to categorise grief are in stark contrast to one of the widest held concepts in grief research – the 'unique and subjective quality' of grief (Worden, 2009). Key reviews of thanatological literature have agreed that grief experience is as unique as the circumstances of the death, characteristics of the death and the bereaved individual and the provision and availability of support (Sanders, 1993; Stroebe & Schut, 2001). The unequivocal conflict between the attempts to delineate 'normal' grief and the assertion that all grief experience is unique represents a fundamental paradox in the grief literature (Breen & O'Connor, 2007).

The proposal to include a PGD diagnosis in the DSM-V has met with fierce opposition from clinicians and researchers and been the focus of two recent editorials in the *Lancet* (Frances, 2012). Ben-Zeev, Young & Corrigan (2010)

express concern that the diagnosis may narrow the range of 'healthy functioning'. They also highlight that the potential treatment gains associated with a PGD category of diagnosis, may be outweighed by the risk of pathologising individual differences and diversity in human behaviour. Stroebe & Schut (2005) highlight the real concern that the death of a loved one will be placed in the realm of psychopathologies. Dr Allen Frances, one of the most vocal critics was the Chair of the Task Force for DSM-IV, whose primary argument centres on the potential for the medicalisation of normality and the subsequent unnecessary psychiatric labels placed on bereaved individuals (Frances, 2012). A recent editorial featured in *The Lancet* (2012), a medical journal, stated that the medicalisation of grief, to include the legitimised treatment with antidepressants, is not only dangerously simplistic, but also flawed. However, the complete dismissal of all the serious signs of major depression as a normal part of the mourning process risks the failure to recognise the sometimes-harmful extremes of a grief response (Fox & Jones, 2013), where professional support is legitimately required.

1.9 Understanding the experience of grief: the challenge facing therapists and researchers.

Following widely cited claims that grief counselling is 'typically ineffective, and perhaps even deleterious' (Neimeyer, 2000, p541), a major meta-analysis was conducted on 61 outcome studies which concluded that grief therapy has little or no effect for clients with less oppressive and sustained symptoms, but can benefit those clients who are assessed as contending

with significant clinical distress (Currier, Neimeyer & Berman, 2008; Neimeyer & Currier, 2009). Research evaluating satisfaction with Cruse bereavement counselling revealed that six weeks after the end of counselling, 89% clients felt the loss less intensely; 88% experienced fewer physical symptoms; 81% felt less anxious, 85% found it easier to cope; 72% felt more confident, 86% were more able to relate to others and 80% were more able to look to the future (Gallagher, Tracey & Millar, 2005). Although these results demonstrate impressive satisfaction rates, Schut & Stroebe (2010) advise caution as they are based on satisfaction measures rather than the effects of interventions and therefore may risk accounting for natural change rather than change attributable to the intervention.

Currier et al's (2008) meta-analytic review has since been criticised for using an invalid statistical technique (Hoyt & Larson, 2010) but other studies concur that therapeutic interventions are generally more effective when the client is high-risk (Schut & Stroebe, 2010), has complicated grief reactions (Jordan & Neimeyer, 2003), is experiencing chronic grief, has experienced bereavement through sudden or violent death (Worden, 2009) and has self-referred (Allumbaugh & Hoyt, 1999).

A clear misalignment has been identified between contemporary grief research and grief counselling practices, disparity between which may impact grief intervention effectiveness. Research has found that grief counsellors continue to be influenced by classic grief theories and the grief work hypothesis (Breen, 2010), have a reliance on stage and task models and hold a belief that a client can become 'stuck' within a specific stage,

despite acknowledging that grief experience is unique to each client (Payne, Jarrett, Wiles & Field, 2002). This is partly explained by the fact that despite journals being the most popular way to disseminate the latest research on interventions, they were rated as least helpful in the practice of service providers (Bridging Work Group, 2005).

This disconnect carries significant cause for concern because specifically targeted grief interventions, informed by a meaning reconstruction conceptualisation of grief, have been found to be particularly effective for complicated grief reactions (Matthews & Marwit, 2004) and yet are not reflected in practice. For example, Shear, Frank, Houck & Reynolds (2005) have developed a tailored complicated grief treatment (CGT), informed by the dual process model (Stroebe & Schut, 1999), which involves a series of interventions to facilitate adaptive oscillation between orientation to the loss and restoration of contact with a changed world. In research conducted over 16 weeks, CGT produced twice the rate of improvement in clients compared with those who received a more general form of psychotherapy (Shear et al, 2005). Niemeyer & Currier (2009) cite a promising new direction in grief intervention research, which takes a cognitive-behavioural approach to complicated grief. Preliminary findings from research comparing cognitive behavioural interventions with supportive counselling indicate that a combination of cognitive restructuring (focusing on identifying, challenging and changing negative cognitions) and exposure therapy (confronting reminders and elaborating on the implication of the loss) is significantly more effective for clients presenting with complicated grief than supportive counselling (Boelen, de Keijser, van den Hout & van den Bout (2007).

Prioritising an approach that facilitates the dissemination of recent theoretical developments into clinical practice is therefore likely to benefit both clients and service providers by improving the efficacy of interventions.

1.10 Implications for theory and practice of understanding grief as a stage-based reaction: feeling 'stuck' in grief

Breen & O'Connor (2007, pp.202) assert that "the prevailing construction of grief, endorsed by laypersons and mass media, remains a stage-based reaction, where recovery occurs within a relatively short time frame, where there are normal and abnormal reactions to grief, and continued attachment to the deceased is pathologised." It is therefore suggested that reports of feeling 'stuck' in the grief process will likely be experienced in the context of this construction of grief. Aversion to 'social pain', defined as the "specific emotional reaction to the perception that one is being excluded from desired relationships or being devalued by desired relationship partners or groups" – is argued to be a powerful motivating force for compliance to social norms (MacDonald & Leary, 2005, p. 202). The sense of shame when deviating from social norms associated with bereavement can be internalised by grieving individuals, leaving them feeling frustrated with a sense that they are not moving on (Harris, 2010). Despite research confirming the diverse factors implicated in the various reactions to loss, it is argued that bereaved individuals in Western society still grieve in the context of social expectations of conformity and uniformity (Harris, 2010). Specifically, the categorisation of PGD based on an assumption that 'normal' grief reactions are confined to

six months (Prigerson et al, 2008), may impose the concept of feeling stuck on bereaved individuals.

Despite the lack of consensus in the literature surrounding PGD and theories of grief, the concept that individuals can become 'stuck' is common to most researchers and practitioners in bereavement. The Dual Process Model (DPM) views chronic grievers, associated with rumination and preoccupation with thoughts of the deceased, as stuck in loss orientation, with little or no oscillation to restoration tasks (Stroebe, M., Schut & Stroebe, 2005). Individuals with PGD are conceived to be stuck in a state of chronic mourning (Prigerson et al, 2008), appear stuck in their anguish for extended periods (Holland, Neimeyer, Boelan & Prigerson, 2009, Wolff & Wortman, 2006) and cannot proceed through the normal bereavement process (Howarth, 2011). The phenomenon referred to as bereavement overload is thought to leave relatives overwhelmed and stuck in their grief as multiple bereavement deprives them of their natural support system (Neimeyer & Holland, 2006).

1.11 Research Questions

Despite this consensus on the potential for bereaved individuals to become stuck, the meaning that individuals attribute to those feelings of being stuck remains unexplored in grief literature, as does the nature and origin of expectations about the grief process. Recent developments in grief theory highlight the centrality of meaning-making in adaptation to negative and highly stressful life events, and the importance of recognising individuals'

experience and understanding this, within the context of their cultural and social norms. This study therefore requires a research method that respects and identifies with the centrality of meaning-making evident in grief research. IPA is an example of such a methodology as it locates sense-making activities as the basis for learning about one's relationship to the world with a focus on meaning and communicative action (Smith et al, 2009). An IPA study is therefore proposed which aims to explore the following research questions:

1. What are the meanings and constructions underlying narratives on feeling stuck in the grieving process?
2. What is the nature of the interplay between grief experience and expectations about grief?
3. What is the nature of the interplay between feelings of being stuck and the responses from family members and friends to these feelings of being stuck and to the event of loss itself?

Chapter Two

Methodology

This chapter presents the rationale for choosing the research paradigm of hermeneutic phenomenology and the research methodology of Interpretative Phenomenological Analysis (IPA). The research design framework is also outlined detailing ethical considerations, quality assessment criteria, sampling and recruitment of participants, data collection and data analysis. Personal reflections on the process of conducting an IPA study are included in grey font throughout the chapter to promote transparency and cohesiveness.

2.1 Research Paradigm – Why Hermeneutic Phenomenology?

The chosen paradigm from which the research is conducted is phenomenology, specifically the hermeneutic and existentialist phenomenology informed by Heidegger (1962). Hermeneutic phenomenology is positioned between the realist and relativist paradigms where experience of phenomenon is viewed as the product of interpretation (Willig, 2008). Phenomenology is a philosophical approach to the study of lived experience, where experience is explored within its specific context and in its own terms. Smith, Flowers & Larkin (2009) cite the rich source of ideas on how to examine and understand lived experience as the key value for psychologists. Heidegger's phenomenology emphasises interpretation as the primary method and is therefore seen to converge with the tradition of

hermeneutics. Heidegger's (1962) philosophy is particularly relevant to this study of grief as his existential focus sees death as providing a temporal dimension to our subjective experience and 'being-in-the-world'.

Phenomenology was chosen over realism as a positivist approach would not only directly challenge the widely held notion that an individual's grief has a 'unique and subjective quality' (Worden, 2009, p9), but would also fail to address the overall aim of the research: to explore the meaning that individuals attribute to the phenomena of feeling stuck in their grief. Valentine (2006) argues that this approach can also medicalise grief as it excludes subjective experience and ignores how individuals make sense of their world.

Although a relativist approach would effectively challenge the positivist notion that individuals share one experience of grief encapsulated by a stage theory, social constructionism's primary focus would always be the effect of the language, compared to phenomenology's focus on the meanings of the language. The latter approach was therefore deemed more congruent with the research questions and can offer meaningful insights through interpretation (Smith et al, 2009).

2.2 Research Methodology – Why IPA?

The contention between hermeneutic phenomenology and phenomenology provides weight to Madill, Jordan & Shirley's (2000) argument for epistemological clarity in qualitative research and is born out in Osborne's

(1994) emphatic calls for phenomenological methodologies to reflect the chosen philosophy throughout the research process. I therefore selected Interpretative Phenomenological Analysis (IPA) as the most appropriate research methodology as Smith et al (2009) have been explicit about the philosophical influences of phenomenology, hermeneutics and its ideographic perspective.

IPA was conceived as an experiential and qualitative method for psychologists, championing a research focus on the human predicament (Smith et al, 2009). Smith (2011b) cites the motivation for developing IPA in the mid 1990s as striving for a rich and detailed portrayal of personal experience, something he felt psychology research had failed to achieve.

IPA is phenomenological evidenced by it's focus on the interpretation of meaning-making activities (Smith et al, 2009) and its concern with individuals' perceptions of objects or events. Smith et al (2009) view phenomenology as a pluralist endeavor, and have been inspired by the work of the most prominent phenomenological philosophers: Husserl, a influential philosopher inspired to discover the essence of conscious experience; Heidegger, a student of Husserl whose direction in phenomenology emphasised interpretation; Merleau-Ponty, who situated the body as a central element in experience; and Sartre, another student of Husserl, extends the notion of existential phenomenology (Smith et al, 2009). The three latter philosophers were particularly influential in IPA as they take phenomenology from the descriptive to an interpretative position. This approach recognises the central role for the analyst in making sense of that

personal experience and is thus, strongly connected to the hermeneutic tradition (Smith, 2004).

Hermeneutics, the theory of interpretation (Smith et al, 2009), forms the second major theoretical underpinning to IPA. It provides space for a researcher to reflect on the nature of the relationship between fore-understanding and the phenomenon itself and allows for the process of analysis to be iterative. The third and final influence underpinning IPA research is Idiography. This approach differs from traditional nomothetic psychological research, which seeks to generalise results to a population. IPA takes an idiographic approach through its dedication to the particular, both in the sense of understanding a specific phenomenon in a specific context and in the sense of carrying out systematic and detailed analysis.

Since the first publication of an IPA paper in the mid 1990s (Smith, 1996), the rate of publication has accelerated significantly, initially in the UK but now globally, to a situation where the number of IPA studies in peer reviewed journals had totalled 293 by 2008 (Smith, 2011a). It has therefore been argued that it now assumes a dominant position within qualitative research (Hefferon & Gil-Rodriguez, 2011; Willig, 2008) with the two largest domains being health and clinical/counselling psychology (Smith, 2011a).

Smith's (2011a) assertion that IPA's *raison d'être* is lived experience which is of some existential import to the participant, provides a case for employing IPA in a study focusing on loss and grief. IPA is aligned to the theoretical foundations of an existential approach as it posits that experience can be

understood by exploring the meanings attached, which in turn illuminates the existential domains of psychology (Smith, Flowers & Larkin's, 2009). The selection of IPA is further supported by its applicability to other studies of bereavement (Golsworthy & Coyle, 2001; Begley & Quayle, 2007; Reilly, Huws, Hastings & Vaughan, 2008) and by Nadeau (2008) who suggests that approaches with phenomenological sensibilities are particularly relevant to studies of meaning-making in bereavement.

2.3 Embedding Quality into the Design

Despite a rise in popularity of the qualitative paradigm in bereavement research, literature reviews within the field reveal an enduring legacy of the positivist tradition, where concepts usually associated with empirical research such as variables, control groups and validity are used in reference to assessing qualitative research design (Parkes, 1995, Stroebe et al, 2003, Stroebe et al, 2008). In order to ensure that my research consistently reflects my epistemological position of hermeneutic phenomenology and remains consistent with the underpinning principles of IPA methodology, all stages were conducted in alignment with Yardley's (2000) guiding principles for quality in qualitative research. These principles are (i) transparency and coherence, (ii) commitment and rigour, (iii) impact and importance and (iv) sensitivity to context.

Sensitivity to context was addressed in two ways: firstly, the literature review in Chapter 2 communicates a comprehensive understanding of the historical assumptions and categories that have been applied to grief and

bereavement. This is an important pre-requisite on which to base the hermeneutic aspect of IPA, where added-value interpretation comes from an oversight of the 'whole' (Smith et al, 2009). Secondly, the idiographic roots of IPA emphasise the importance for the research to remain sensitive to the participant as an individual and to view their experience as unique. This has been addressed through reflexivity and transparency throughout the research process from the recruitment of participants, the interview process and the interpretations made in the analysis phase.

Linked to reflexivity is ensuring *transparency and coherence* in both the process of research and the resultant write up. By taking a hermeneutic phenomenologist position, I acknowledge that my experience and 'fore-understanding' is embedded in my interpretations (Heidegger, 1962) and therefore advocate transparency and reflexivity. The write up of my research therefore includes a discussion of my epistemological position, my position on grief theory and practice, and a detailed description including reflections on the data collection and analysis stages. These reflections are integrated throughout the methodology in grey font and are written in the first person.

Part of addressing the *commitment* and *rigour* of research includes taking care to theoretically align the sampling with the orientation of the methodology. Other aspects of ensuring the research was carried out with rigour include completeness of interpretation and in recognising the value of using intuition and imagination.

The concept of feeling stuck in the grieving process is popular within contemporary grief literature (Wolff & Wortman, 2006; Prigerson et al, 2008; Worden, 2009). In order to ensure the research has *impact and importance*, it was crucial for the results to effectively communicate the unique meaning-making, experiential aspect of this research, which will distinguish it from the pervasive pathologising perspective. IPA's ideographical influence helped in achieving this goal, through its commitment to understanding a phenomenon from the perspective of particular people within a particular context (Smith, et al, 2009).

2.4 Ethical Considerations

Ethical approval was sought from both University of London's ethics committee and from Cruse Bereavement Care Head Office. Approval was granted from UEL on 5th August 2011, by Cruse local branch on 25th July 2011 and Cruse Head Office on 2nd August 2011. (Appendix I)

Two ethical considerations for participants were identified and precautions outlined in the ethics approval process for this research. The first was the potential for participant distress during the research interviews due to the emotive content being discussed. Participants were informed about the type of questions that they could expect when booking the interview over the phone and were given the opportunity to read and digest the aims and procedures of the research ahead of the interview as part of the informed consent. The participants were informed that they were able to stop the interview at any time or to refuse to answer any questions if they felt that

answering it may cause them distress. No participants chose to stop the interview or withdraw their consent. The potential for the participants to express deep sadness was also prepared for and two participants did sound distressed at times during their interview. At the end of these interviews, a check was made that they had an appointment with their Cruse volunteer supporter within the next week and that they had the number of the Samaritans if they felt they needed support in the mean time.

The second potential hazard highlighted for participants in this research was the possibility of blurring boundaries between the nature of the interview conversation as research versus the interview conversation as a counselling task. The dilemma faced by qualitative researchers: that research interviews on sensitive topics can become therapeutic in nature, is perhaps unsurprising given that it gives participants an opportunity to tell their story to someone who is listening, helps them to put their story in context and to make sense of what has happened to them (Drury, Francis & Chapman, 2007). However, a research interviewer must respect their ethical responsibilities towards a vulnerable population by avoiding the blurring of these boundaries (Murray, 2003). This was addressed in the current study by discussing the objectives of the interview and highlighting the distinction between the interview and their future therapeutic support offered by Cruse Bereavement Care. The informed consent was discussed and reference was made to their allocated Cruse volunteer supporter, with whom they could discuss any issues that came up during the interview, including any risk issues that emerged.

Ripley (2001) refers to the tension that research interviewers have a responsibility to manage, between the need to collect data on a specific topic and the need to engage in the 'here-and-now' interactional event. Maintaining an awareness that the interview is an interaction is a minimum requirement for researchers (Potter & Hepburn, 2005) in addition to being mindful during the analysis phase that the resultant 'talk' is a product of this interaction (Ripley, 2001). Further reflections on the effect of the interview questions, types of questions and the role of the interviewer in this study are explored in the Discussion Chapter, section 4.5.

2.5 Research Design Framework

2.5.1 Sampling and Recruitment

Care was taken to align the sampling to the orientation of the IPA methodology used, therefore Purposive Homogenous sampling was employed during the data collection phase (Smith et al, 2009). Achieving homogeneity for this research was subject to limitations such as access to participants, and dependency on self-selection. This has resulted in the following 4 factors being defined for sampling purposes: 1) Adults (over 18); 2) Bereaved for over 6 months; 3) Individuals who have sought bereavement support from Cruse Bereavement Care 4) Report feeling stuck in their grief process.

Following approval in a presentation to the Cruse Management Committee for the local Area, the referrals secretary, supervisors and volunteers were invited via supervision groups to identify new clients who had been bereaved over 6 months, aged over 18 and were reporting feeling stuck in their grief.

Advertising leaflets for volunteers (Appendix II) were distributed to volunteers to explain the research and the inclusion criteria, and separate leaflets for the participants were provided (Appendix III) for volunteers to distribute. In order to improve recruitment of participants in the later stage of data collection, two other Cruse branches were approached and a presentation was made at the local Cruse Annual General Meeting.

Smith et al (2009) propose a typical sample size of between 4 and 8 interviews for Professional Doctorates, and a target sample of 6 interviews was established prior to data collection. Between January and November 2012, six clients were identified for meeting the inclusion criteria and of the six participants identified, five agreed to be interviewed. The digital recording of the fifth interview was corrupted during file transfer to the computer so the research analysis proceeded with a sample size of 4.

The final sample size of 4, although within the acceptable range suggested for IPA research by professional doctoral students (Smith et al, 2009), is lower than expected but can be justified in two ways. Firstly, there has been a recent drive supporting smaller sample size in IPA research as larger numbers of participant accounts are thought to undermine IPA's idiographic commitment and can lead to a shallower, more descriptive analysis (Hefferon & Gil-Rodriguez, 2011). Secondly, the richness of the interviews and in-depth analysis of such an emotive subject are considered to counteract any impact from having a smaller sample size. The richness of information was addressed through engaging in purposive sampling, specifically the recruitment of both *appropriate* and *adequate* participants (Fossey, Harvey, McDermott, & Davidson, 2002). The *appropriateness* of participants, defined as 'those who

best inform the topic', has been addressed through the targeted recruitment of participants who self-reported as living the experience of feeling stuck in grief. The *adequateness* of the participants in this research, defined as 'sufficient to address the research questions and provide a full description of the phenomenon', was evidenced in the transcripts. All four participants were expressive and focused during the interview, providing rich accounts about their experience of their loved one when both alive and deceased, the experience of feeling stuck in their grieving process and about how the experience of their grief compared to their expectations.

I was aware from the start that recruitment for this research could be challenging for two reasons. Firstly, I had no direct method of contacting the clients as I relied on the referrals secretary and volunteers to pass on the leaflets and identify clients who they were in contact with. However, I have been preparing for this research with my local branch of Cruse since 2010 and have been extremely fortunate to have had the unconditional support of the referrals secretary and the administrator throughout the process. Within a day of the presentation to the management committee, three new clients had been identified and referred to me by the referrals secretary, and a week later I received a call from a client who had heard about the research from their Cruse volunteer. At this time I thought I would be overwhelmed by interviews, but I didn't receive another referral for four months despite monthly reminder emails. Following a meeting with the referrals secretary 10 months after the recruitment phase of research had started, I received my sixth and final referral. I learnt a valuable lesson that although the research was

wholeheartedly supported, people's initial interest will understandably fade beneath all the competing priorities involved in running a charity in the absence of face-to-face contact.

In terms of approaching the recruitment differently to improve the recruitment rate in hindsight, the best way to access participants was through face to face meetings with the referrals secretary so monthly meetings throughout the year could have been booked from the start to review the new referrals for appropriateness. An alternative approach, that may have also had the added benefit of helping more individuals access support from Cruse, could have been to distribute recruitment leaflets to GP surgeries around the local area. In this way, they may have identified with the feeling of being stuck, contacted me about taking part in the study and I could have connected them with Cruse for on-going support.

A second reason for concern around the challenge of recruitment was the fact that I was recruiting new clients who had not yet established a relationship with Cruse and were likely to be vulnerable and in a heightened state of emotion. However, this concern proved to be unfounded as only one out of six of the participants chose not to proceed with the interview and this was someone who agreed to receive written information about the research only. The remaining five who I was able to speak to agreed immediately to an interview, saying that they wanted to participate in the hope that the research might help others in similar situations.

2.5.2 Context

Cruse Bereavement Care is the largest bereavement charity in the UK providing free support to anyone bereaved by death helping them

understand their grief and cope with their loss. In 2012, 5,700 Cruse volunteers provided 44,050 people with bereavement support across the UK². The participants in this research were recruited from the South Kent Area of Cruse where 185 clients were provided with support in 2012. The vast majority of clients are supported in their homes.

2.5.3 Introduction to Participants

Participants were given a pseudonym at interview to provide anonymity. Demographic information and details relating to their bereavement were taken at the beginning of the interview.

- 1) Mabel is a 54 year old female whose mother died two years before she was interviewed. Mabel believes her mother was murdered by a physiotherapist's interventions and rejects the inquest's outcome of death from lung cancer.
- 2) Lorraine is 65 year old female whose husband died very suddenly 10 months before the interview.
- 3) Jenny is a 51 year old female whose husband died suddenly following a minor illness three years before the interview.
- 4) Sandra is a 36 year old female whose partner died suddenly at the age of 19, 16 years ago. She has since lost a baby nephew, both parents and her sister.

² Statistics sourced from www.crusebereavementcare.org.uk

2.5.4 Data Collection

Data collection consisted of digitally recorded semi-structured interviews using an interview schedule as a guide with open-ended questions and prompts (Appendix IV). Examples of the questions include:

- *What were the main feelings that you were experiencing at the time of the bereavement, and what feelings are you left with now?*
- *How have family members and friends responded to your experience of 'stuckness'?*
- *You've mentioned that you feel stuck in your grieving and we all have different definitions of feeling stuck, can you describe to me how it feels for you?*

The interviews were held in the participants' homes to minimise disruption, to help them feel as safe and comfortable as possible and followed the Cruse protocol of seeing clients within their own environment. An Information sheet detailing the protocol of the interview (Appendix V) was provided to the participants before the interview and Informed consent (Appendix VI) was obtained prior to the start of each interview, which assured confidentiality through data anonymity and informed participants that they could withdraw their consent and stop the interview at any time throughout the process. The interviews lasted between 64 and 79 minutes. Each participant was debriefed following the interview, which included confirmation of their ongoing support from a Cruse volunteer. A debriefing leaflet was also provided to all participants (Appendix VII). Interview recordings were transcribed and all

identifying details were removed and names were replaced with the nature of relationship e.g. [brother] or [husband].

I was overwhelmed by how open and honest the four participants were during the interviews and just how effectively they conveyed their experiences of pain and loss. Despite working with grief clients for over four years, I still feel moved when the pain surfaces and the individual describes the significance of the love they have lost. I had tears in my eyes more than once during the interviews and in one of the participant accounts, the interview was so emotionally charged that I felt affected by it for several days afterwards. It felt difficult to leave the participants, as in a therapeutic context with my Cruse clients I would return the following week and continue to offer a supportive role but in this context we would not meet again. It was a comfort, however, that they had a Cruse volunteer allocated so ongoing support was in place. During the research proposal phase, I was keen to strike a balance between a desire to cause the least distress to participants who are being asked to describe a painful experience with a desire to capture a dynamic lived experience as opposed to a retrospective account. I am indebted to the participants for allowing me a window into their raw grief experience, which has produced such rich and vivid transcripts.

2.5.5 Data Analysis

i) Reading, re-reading and initial commenting

Data analysis commenced once the first three interviews were transcribed as the fourth interview was conducted 5 months later. Smith et al (2009)

recommend starting with the most detailed and engaging interview and analysing this in detail before moving on to the subsequent interviews. Transcripts were printed on A4 portrait and stuck into an A3 landscape sketch pad. This method of presentation allowed for large margins either side of the text for writing comments and emergent themes. As the most engaging and emotionally charged interview, the interview with Mabel was selected for analysis first. The transcript was read whilst listening to the audio twice, and read twice more without the audio, as listening can contribute to a more complete analysis (Smith et al, 2009). Listening whilst reading allowed the tone of voice to be captured which can help to make sense of the meanings behind the content, for example Mabel used sarcasm to describe her experience of the mental health crisis team:

“Oh that’s really helpful, yeh really really good” (Mabel, line 238)

Without the additional information from the tone of voice, this may have been misrepresented within the analysis. Initial notes were made in pencil in the right hand column during the first reading then, in subsequent readings, Gee’s (2011) colour coded system was introduced for the different types of comments: descriptive, linguistic and conceptual.

Initially I found this process both extremely helpful and extremely challenging as although I like the potential for organisation that it offers it was difficult to determine which category my comment fell into. As I re-read the transcript over several days, distinguishing between comments became easier and the types of comment that I made became more interpretative. I found having time between each reading helped in two ways: firstly it allowed time to reflect on early forming ideas as commonalities were identified and secondly

it provided an opportunity to approach the text with a 'beginner's mind', which reduced the chances of becoming blinkered or biased towards one dominant theme.

ii) Developing emergent themes

The aim of this phase of the research is to move the analysis from open and contingent comments towards capturing an understanding of the transcript as a whole (Smith et al, 2009). During the initial commenting phase, potential themes were written in the left hand column as commonalities within the transcripts became apparent. The themes were then transposed to Post-it notes and grouped by association and similarities on flip chart paper. The Post-it notes were then re-arranged until all them were either in a group, had been discarded (and retained separately) or had been merged with other themes due to overlap.

Individual analysis of the second and third interviews was then carried out following the identical process detailed above. This proved to be an iterative process where the emerging themes would be re-visited until the themes formed a grouped structure. The fourth interview was held during this period, and the analysis followed. As the analysis progressed through each interview, a working draft of a hierarchical, grouped 'map' of emerging themes was created using post it notes until all four interviews' themes featured on the 'map'. This 'map' became the main tool of cross case analysis where different combinations of themes and master themes were trialed and this process was repeated several times until a coherent and robust structure emerged. Several drafts of the master theme hierarchy were

produced until the final version was completed and the results of the analysis were formalised. Pictorial representations of the draft and final theme hierarchies can be seen in Appendix VIII. Verbatim quotes providing evidence for each theme were extracted from the transcripts and presented in a table (Appendix IX).

The process of connecting parts of the dataset happened naturally during the initial commenting phase, however, once the focus was solely on emerging themes and the initial comments became part of the data set, the more subtle concepts emerged. This part of the research process was the most exciting, I found it difficult to take breaks and at times was overwhelmed by the feeling that I couldn't capture the essence of the theme in words before it faded and was replaced by another idea. A slightly uncomfortable bi-product of the exciting and imaginative phase for me was the chaotic and disconnected way in which the themes would emerge. To help negotiate this chaos, I felt I needed to see all the themes together and play with them in different groupings physically so I used Post-it notes. From this stage, my progress seemed to leap ahead. During this period, I held an informal workshop with a peer where we interrogated and debated each theme and the rationale for grouping, asking: does this theme have enough substance to stand alone? Do any themes overlap to the extent that they could merge? What binds these themes together and is there enough evidence for that grouping? This time was invaluable for me to stand outside my data analysis and to challenge each interpretation I had made to date. I followed this workshop up with a supervision meeting which acted to further refine the theme groupings.

I found creating titles for each theme and master theme challenging in terms of being time consuming but also stimulating, as it demanded different skills like creativity and synthesising. I chose to use the participants' vivid and emotive metaphors for many of the theme titles as they seemed to capture the meaning behind the data so effectively. One of these metaphors used by Sandra was so evocative of the stagnancy that grief left her feeling that I used it for the thesis title: "doing the same puzzle over and over again" (Sandra, line 375).

Although the analysis closely followed Smith et al's (2009) procedures for IPA, the emergent master and subordinate themes offer one subjective interpretation of the phenomenon of feeling stuck in grief based on a specific sample of participants. The themes that emerged during this analysis involved a double hermeneutic (Smith & Osborn, 2008) whereby the researcher was making sense of a participant, who was making sense of their experience of feeling stuck. The researcher's analysis of the participants' subjective responses, although grounded in the verbatim transcripts, was realised through their own "experientially-informed lens" (Smith et al, 2009, p36).

The master themes and their subordinate themes presented in Chapter 4: Analysis are supported by verbatim quotes from the interview transcripts. The themes are interlaced in sequence to provide a meaningful narrative about the lived experience of feeling stuck in grief.

2.6 Concluding comments

This qualitative study takes an epistemological approach of hermeneutic phenomenology, positioning itself directly between the paradigms of realism and relativism. While prioritising transparency throughout the process, this IPA research used purposive homogenous sampling to recruit participants who met the inclusion criteria for semi-structured interviews. The interview transcripts were analysed following the steps, outlined by Smith et al (2009) and Gee (2011), of reading, re-reading and commenting, developing emerging themes and cross case analysis. The analysis is presented in Chapter 3 and the implications and limitations of the analysis are discussed in Chapter 4.

Chapter Three

Analysis

3.1 Overview

This chapter presents the results of an interpretative phenomenological analysis (IPA) of semi-structured interviews with four female participants who sought support from Cruse Bereavement Care and reported feeling stuck in their grief. Four master themes and 12 subordinate themes were identified.

3.2 Introduction to the Themes

The four master themes provide an account of the participants' experience of feeling stuck in grief. The first master theme highlights the fragility and diminishment, that all the participants experience, of their own identity whilst at the same time seeming to prioritise an idealised representation of their deceased loved ones. The second master theme introduces the pervasive sense of powerlessness they experience as a result of the sudden loss of the deceased, and the ways in which they attempt to regain some control. There is an underlying conflict linking the first two master themes between the vulnerable and passive role that the participants perceive themselves to be in where they appear powerless, and yet they can feel impelled to take on a responsibility and entitlement for representing their love for the deceased. The third master theme summarises the double-edged sword coping behaviours that the participants engage in which temporarily provide relief

from the conflicting thoughts and emotions described in themes 1 and 2, but eventually act to isolate them from others and precipitate a feeling of being stuck in a vicious cycle. Finally the fourth master theme ties all the previous themes together by describing how the unresolved conflict and resultant 'stuckness' manifests as an impending doom, loneliness and stagnancy.

3.3 Eclipsed by the deceased

3.3.1 Idealizing the deceased

3.3.2 'They were part of me': loss as amputation

3.3.3 Fear of letting go

3.4 The power in powerlessness

3.4.1 Feeling out of control

3.4.2 Feeling let down by others

3.4.3 Feeling obliged to 'get on with it'

3.5 The double edged sword of coping behaviours

3.5.1 'Locked Inside': Negating emotions

3.5.2 'Like Worzel Gummage': Avoidance as relief

3.5.3 Prioritizing others over self

3.6 Living in purgatory

3.6.1 Impending doom

3.6.2 Loneliness

3.6.3 'Doing the same puzzle over and over again': Stagnant

3.3 MASTER THEME 1: Eclipsed by the deceased

This cluster of sub-themes refers to the way that the participants appear to be eclipsed by their loved ones after their death. The deceased take on an elevated position through being idealised by the participants, and this fantasised representation acts to diminish the participants' self worth as their own life is negated and dominated by an apparent need to keep the deceased 'alive' in their internal world. The sub-themes also capture the underlying tension between the sense of responsibility and entitlement that the participants experience about being the only one to represent the deceased in the world, and the sense of being overwhelmed and fragile as a response to being eclipsed.

3.3.1 Idealising the deceased

Within their descriptions of the deceased, each of the four participants described their loved ones in an idealised way where they appeared to hold them in an elevated position and only recall the positive. This is illustrated by Lorraine's comparison of her grief for her husband with her children's grief for their father:

"I'm not saying they don't grieve, and I'm not saying they don't find it hard, but for me he was sort of like the centre of my universe if you like" (Lorraine, lines 435-437)

Lorraine's use of the universe metaphor positions her husband as the equivalent of the sun, around which all planets revolve and the death of which would result in death of all other life. This powerful metaphor conveys the extent of love and dependency bestowed on her husband, and the exclusivity that she feels about their relationship. There seems to be a heavy weight of responsibility on Lorraine for grieving the loss of her husband and perhaps a sense of entitlement about the scale of her grief, as she notes that she is the only one who has lost the centre of her universe. This sentiment is shared by Sandra when describing the feelings she had for her partner who died over 16 years previously:

"I felt that he was the one, end of, one do you know what I mean, we used to see each other every day. Um, I just thought he was the one"
(Sandra, lines 13-15)

Sandra's repetition of 'the one' and the sense of finality from her use of 'end of' seems to elevate her partner and their special relationship. Just as Lorraine's husband represented the centre of her universe, Sandra's extract alludes to the enduring responsibility of grieving her only opportunity for true love. Mabel also elevates her mother to such an esteemed position that she considers herself to be lifeless:

"I haven't got a life now. My whole world ended when my Mum died, she was my best friend. She wasn't just my Mum, she was my best friend." (Mabel, lines 293-294)

Mabel saw her mother as much more than a parent, the loss of whom therefore seems to represent the loss of everyone worth living for. Bearing the responsibility for grieving the loss of her mother and best friend is overwhelming for Mabel as she feels her own life being extinguished. Just as Mabel's mother represented multiple relationships for Mabel, Jenny had a similar understanding of her relationship with her husband, as he symbolised an older father-like figure:

“He was a little bit authoritarian character and I suppose to some extent was a little bit of a father figure. I mean he wasn't a father figure but because he was older than me, there was that sort of... [husband] did certain things and I...I suppose I took his lead on things so that's been quite challenging”. (Jenny lines 99-103)

The power differential that Jenny refers to within their marriage when her husband was alive, seems to live on after his death as she struggles without his authority and leadership. Each of these extracts convey a sense of dependency and idealisation where the loss of their loved ones triggers a diminishment of their own lives. It seems that as the deceased looms larger and larger as an idealised figure, the bereaved participants' feel an overwhelming responsibility to match their grieving to the burgeoning representation. This may leave them feeling diminished in a comparison to the magnitude of their losses; evidenced in Lorraine's loss of the 'centre of her universe', in Jenny's loss of the father figure who always took the lead, and Mabel's loss of anyone worth living for. However, at the same time they seem to have a sense of entitlement that others do not share or can

comprehend the extent of their grief. The ambiguity of feeling eclipsed and less valid yet responsible and entitled runs through the first Master Theme. The next sub-theme is intrinsically linked with idealising the deceased, as the comparison between the loss of their loved ones to the loss of critical parts of their body demonstrates both the significance of the relationship and just how much the deceased represents.

3.3.2 “They were a part of me”: loss as amputation

Common to three of the participants is the feeling that part of themselves has been lost since the death of their loved one, and two use amputation as a metaphor for the pain associated with losing their loved ones. The paradox for the participants is that the deceased seems to be both everywhere and nowhere; idealised to a deified presence as described in the previous sub-theme, yet physically absent leaving the participants feeling ripped apart. Lorraine describes her feeling of incompleteness since the death of her husband:

“Half of me is missing. [] That’s how I feel. You know sort of, we went together. And I just feel that I’ve lost my arm or something, I just don’t feel complete”. (Lorraine, lines 182; 185-187)

It seems that Lorraine saw her and her husband’s lives as so entwined that they almost operated as one body, so when he died she felt as if half of her own body had gone with him. Similarly, Sandra perceived the deceased to have been part of her body:

“They were a part of me, like an arm, a leg do you know what I mean, I have...a part of the puzzle in my heart that’s made me. “(Sandra, lines 444-446)

Sandra and Lorraine both compare the loss of their loved ones to the loss of parts of their body that enable them to function, which affirms the heightened position that the deceased continues to represent. It also contributes to the sense of being obscured by the deceased, where the deceased meant so much to the participants that their loss is felt as a mutilation to their body. For Jenny, her sense of self was eclipsed by the death of her husband:

“you become a partnership, you know, whether it’s a good or bad partnership you know you operate together. [] And so you lose a sense of who you are.” (Jenny, lines 283-287)

This extract suggests that Jenny defined herself as one half of a partnership and experienced the loss of her husband as the loss of her self worth. This becomes a zero sum game for the participants, as the more they attribute parts of themselves to the deceased and the more they project the deceased to a position of power through idealisation, the less resources they have to carry the responsibility and cope with their grief. It is likely that this is related to the third sub-theme: *Fear of letting go*, as letting go conflicts with the idealised status and the notion that the deceased is integral to their sense of self.

3.3.3 Fear of letting go

This sub-theme refers to the fear expressed by all four participants relating to letting go. The associations they make with letting go vary, and include fears about letting go of the deceased, letting go of their emotions and the implications for their sanity. This sub-theme highlights how differently grief is perceived by each participant: as evidence for their love, as a tormentor that threatens their sanity or as something that once allowed in, may never cease. Lorraine's fear of letting go of her husband is clear when she refers to the increasing distance she feels from her husband as the time passes since he died:

“And, you know, I know it's not even a year yet but there's a psychological thing of having to say he died last year. [] Makes it seem further away. And it makes him seem further away. [] And less accessible and just more remote, and I don't want to lose him and I don't want to forget him”. (Lorraine, lines 325-333)

The use of the present tense in ‘I don't want to lose him’ is particularly emotive as letting go seems to mean losing him over again and forgetting him. The process of moving into a new year seems to have caused Lorraine to perceive a greater distance between her and her husband, and all her focus is on maintaining a connectedness. Sandra shares this fear of letting go of her loved ones:

“So to me I think it would class me as, in my mind as heartless. [] Erm, because that’s my love for them do you know what I mean? [] In there (points to heart). And if I don’t let... you know if I let them go, I will feel that you know that’s part of my love and part of me, that would go as well”. (Sandra, lines 462-469)

It is as if Sandra sees her role as a moral guardian of the deceased, where her pain and grief are evidence of her love, so letting her loved ones go would not only mean loving them less, but she fears losing the part of herself that loves them. This acts to maintain the larger than life representation of the deceased, and reinforces the effect of her own life being eclipsed. Lorraine refers to her early worries about allowing herself to let go of her emotions:

“I felt in some ways if I... let go to grieve, a) it was self indulgent and b) I might not be able to pick up the pieces again”. (Lorraine, lines 380-382)

This extract provides striking insight into Lorraine’s coping to date, where she suggests that grieving for her means weakness and indulgence, and would place her at risk of being so consumed and overwhelmed that the damage to her would be irreparable. Lorraine has already felt as if she has been amputated by the loss of her husband, so it is understandable why she would dread the prospect of further harm to herself. Mabel expresses a related fear of losing her sanity if she let go through a most evocative metaphor:

“And now I just feel...like I’m hanging on the edge of this big dark hole and my fingers...are just my last fragments of sanity and that relentless tormentor called grief is trying to peel my fingers away from the edge of that hole. And I don’t know where I’ll go when my fingers come off”.
(cries) (Mabel, lines 191-194)

Mabel’s metaphor seems to represent the grieving process as eroding her sanity, where she seems unable to sustain the energy levels required to manage the huge emotions she continues to experience. She is not just tormented by the loss of part of herself when her mother died, but also tormented by the process of grief itself as she tries to hold on to parts of herself. Jenny seems to express an understanding that this fear of letting go prevents them from healthy grieving and that it may partly explain her stuckness:

“And I think maybe that’s something to do with being stuck, because there is a time when you have to let some things go”. (Jenny, lines 248-249)

The fear seems to loom over the participants like a judgement on their love for the deceased, as if the pain they feel is judged by themselves and others as proof of their love and therefore must never be relinquished. This fear of letting go can be linked with the previous sub-themes of idealisation where the participants can’t conceive of letting go of such an esteemed love, and with loss as amputation where the physical loss has already been felt and further loss to the self cannot be contemplated.

Master Theme 1: Summary

The common thread that binds the three sub-themes described above is a sense that the participants' sense of self have been eclipsed by an overwhelming, all-consuming, idealised representation of the deceased who is regarded as more important than themselves and occupies a dominant position. The intense connection with their loved ones and the subsequent loss of this is experienced as a physical amputation. However, the emotional bond with the deceased remains and also contributes to the weight of responsibility that they feel to grieve and keep the memory alive of such an esteemed love. The participants interpret their pain and grief as evidence of this love, and so fear letting go of any part of that experience, and as the deceased looms larger their resources to cope with the burgeoning responsibility dwindle. The resulting tension between feeling eclipsed yet responsible and entitled to their grief is further explored in Master Theme 2, which illustrates the participants' responses to their emergent sense of themselves as powerlessness.

3.4 MASTER THEME 2. The power in powerlessness

The tension between two apparently contradictory ideas that permeates Master Theme 1 is equally present in this Master Theme as the participants tend to view themselves in a powerless and passive position at the mercy of circumstances; whilst at the same time, setting high expectations, rejecting others and punitively judging themselves. Three sub-themes were identified that focus on the interplay between feeling powerless and taking back

control: the first sub-theme describes the powerless position in which the participants view themselves and the second and third sub-themes describe the responses to the powerlessness experienced when let down by others and when obliged to 'get on with it'.

3.4.1 Feeling out of control

This sub-theme describes the participants' low perceived control since the sudden loss of their loved ones, and the sense that whatever they do, they are powerless against the constant 'poking and prodding' from grief. The most explicit example of this is given by Lorraine:

"It's like time is moving me on and I'm leaving him further and further behind. Whether I wanna move on or I don't, I haven't got a choice, time is moving me on." (Lorraine, lines 323-325)

Lorraine's repetition of 'time is moving me on' and the explicit expression of having no choice provides a moving insight into the relentless imposition of change that she feels an intense pressure to disconnect from her husband. This pressure would likely be felt as very stressful and exposing as it connects with her fear of letting go described in sub-theme 3.1.3. Jenny recalls a similar lack of choice during the period directly after the death of her husband:

"I think the problem is you don't...unless you've actually encountered it...you know this is my first encounter really...of somebody dying and

being responsible is that erm, you're not really given the choices."

(Jenny, 52-54)

Jenny's use of the word "responsible" seems critical here in illustrating her powerlessness, as it is this weight of responsibility that makes the lack of choice a very uncomfortable feeling to bear. As the responsible adult, they feel they should be the one to make the right decisions and take charge of the situation, and yet they experience an undermining of their power and control and attribute it externally. Mabel's lack of perceived control is strongly evident in her use of this metaphor:

"that relentless tormentor called grief is trying to peel my fingers away from the edge of that hole. And I don't know where I'll go when my fingers come off. (cries) [] Just go along, grief and pain keep poking you and prodding at you all the time, trying to lift my fingers off the edge" (Mabel, lines 193-198)

Grief and pain seem to be experienced as an external 'tormentor' for Mabel, and not as part of her internal world of thoughts and feelings. In the 'dark hole' metaphor she is using her arms to hold on, so conveys a sense of being utterly powerless to defend herself against the perceived attack. This sub-theme summarises the lack of choice and control that the participants feel, yet at the same time they feel that they should be taking charge as they feel entirely responsible for representing the deceased. This resentment and frustration about the lack of choice and control is linked to the next sub-theme of feeling let down by others where the loss of agency is thought to be

a key driver of establishing high expectations of others and subsequent disappointment.

3.4.2 Feeling Let down by others

Experiences of feeling let down are representative of the bitterness the participants are feeling towards others for not understanding their situation well enough, for not listening properly, for not caring enough and for not measuring up to the deceased. It seems likely that the loss of agency and powerlessness described in the previous sub-theme leaves them feeling vulnerable, exposed and entirely dependent on others for survival, and so to manage these consuming emotions the participants attempt to regain some control by positioning themselves as misunderstood and elevating their expectations of others. The extract below is one of many examples that Mabel provided that refer to the lack of service and support she has experienced since the death of her mother:

“I went for counseling at the Hospice...pointless. [] She said ‘I am seeing a woman that is absolutely distraught with grief’. I know that, that’s not why I’m here, you know this is just ridiculous. My God, I think I went there four or five times, this is pointless, absolutely pointless.”

(Mabel, lines 263-268)

Mabel’s critical assessment of her counsellor’s approach is revealed by her use and repetition of ‘*pointless*’ and is resonant of the anger she expresses about the circumstances surrounding her mother’s death evidenced

throughout the transcript. The powerlessness that she has experienced since the loss of her mother is likely to have contributed to her distress, but perhaps what is illustrated here is an example of how Mabel has found a way to empower herself by dismissing the counsellor. The resentment felt towards others is further revealed in the following extract from Mabel:

“I feel sorry for anyone that’s got to come to talk to me, I do. You know, that’s why people don’t come and talk to me. Who the hell wants to talk to someone that’s crying? No one. It’s depressing isn’t it, really. Sure people have got better things to do, and I used to have. But I like to think, when I was ok if anyone had been in this state, I would have spent, I would have given them some of my time”. (Mabel, lines 651-656)

This extract exemplifies the resentment that Mabel experiences when people did not visit her. She initially seems to have an understanding about her lack of visitors in this extract, which contrasts with the subsequent sense of being let down, having expected more from people. It seems that Sandra attempts to minimise the chance of being let down by restricting the opportunities:

“Because I only let you have one chance and if you blow it [points to front door]. It’s because of my insecurities and trust”. (Sandra, lines 922-923)

Both Mabel and Sandra have responded to the sense of powerlessness that they have experienced through the loss of their loved ones by attempting to

regain control in other ways such as establishing high expectations and rejecting people that don't meet them. Though this may act to reduce their feelings of vulnerability, it is likely to create distance between themselves and others, which may increase the risk of isolation and stagnancy described in Master Theme 4. Another way the participants have expressed their disappointment in others is the frustration that people don't understand their grief, illustrated here by Lorraine who reached out one night for help from a national emotional support service:

“ah bless his heart I got a young chap, well he sounded young and he obviously...well he said he had no idea...no experience, personal experience of bereavement. So, with the best will in the world, he couldn't empathise” (Lorraine, lines 513-516)

Lorraine's patronising tone in '*bless his heart*' and '*with the best will in the world*' evokes a sense of her experience of grief being beyond others' comprehension. This perception of difference is likely to create a distance between the participants and the 'other' who is failing to help, listen, or understand. This sub-theme about feeling let down by others may be reflective of the participants' intention to regain some control. However, by establishing high expectations of others, maintaining distance from others and criticising those who do not meet their expectations, may paradoxically increase their isolation. So, this expression of potential resilience appears to remain unassimilated in their identity and further contributes to their sense of powerlessness.

3.4.3 Feeling obliged to 'get on with it'

The rules of grieving that exist as part of our global meanings structure can be passed on by religious texts, family, friends and the media or be internalised as a punitive, self-critical voice. This voice was evidenced in all four of the transcripts, and implies that they *should* be able to cope with their grief by just getting on with it. These rules and the punitive voice are presented in such a way that the participants perceive themselves as left with little choice but to follow them, which likely leaves them feeling both powerless from the obligation to get on with it, and yet at the same time powerful and controlling as the directive tone of the voice conveys. The extract below illustrates how self-critical Lorraine is:

“If I cried I sort of thought ‘for goodness sake [Lorraine], pull yourself together, get on with it, you’ve got to get on with it. You know, ok so he’s died, so tough that’s the way it is. You’ve got to get on with it”.

(Lorraine, lines 386-388)

Lorraine’s use of harsh and punishing words acts to minimise her experience and convey her belief that any emotional expression of grief is negative. ‘You’ve got to get on with it’ seems to be used as a mantra, considered capable of creating change, but this apparently powerful self-talk is merely superficial and can’t overcome the powerlessness as a result of the inherent lack of choice. This unforgiving self-talk is also used by Jenny:

“Because you’ve got to grin and bear it in a way. I mean you’ve just got to get on with it. [] And you know that you’ve got through the first year, you know that the sort of emergency’s off in a way” (Jenny, lines 545-549)

This extract from Jenny seems to convey more of a sense of obligation and powerlessness behind the mantra-like speech. The tension between being in a powerless position, yet attempting to regain control over their life pervades this sub-theme of ‘*feeling obliged to get on with it*’ and would likely result in dissonance for the participants. Sandra’s use of the mantra to live for today, and forget about tomorrow and yesterday appears on the surface to be a judgment on others’ ability to cope:

“I find, you know, a lot of people do that and it’s not very good for them, they should look, you know, for today. Forget about tomorrow and yesterday. Live for today, and that’s what people should do because that’s what a lot of people do: get into depression, due to being stuck, thinking about the past, what happened in the past.”(Sandra, lines 351-355)

On closer analysis, it appears that the obligation is aimed at herself as she has described herself as stuck in the past, and reveals later in the interview that she has been depressed, abused as a child and has lost all her close family. Understanding the covert meaning in this extract allows us to glimpse the conflict that Sandra may feel as she fails in her efforts to overcome the powerlessness and live in the moment as she feels she should. Mabel

describes her experience of one of the most widely communicated rules of grieving:

“I just didn’t feel any better and as the time goes on the pain gets worse and they say time heals. It doesn’t” (Mabel, lines 579-580)

For Mabel who has been grieving the loss of her mother for two years, the belief that time heals has been of little comfort and the implicit rule represents a constant reminder that although feeling powerless to heal the pain, she *should* be healing.

This sub-theme has revealed the conflict that participants may experience when they or others apply the implicit rules of grieving to their situations. These rules include that you should feel better over time, you should be able to cope by now, you shouldn’t burden others with your grief, and that you should leave the past behind and live for today. These rules of grieving give rise to the punishing self-talk in the form of mantras that the participants engage in and elicits conflict with the overwhelming sense of powerlessness they feel from the sudden loss of their loved one and the lack of choice to accept it.

Master Theme 2: Summary

The three sub-themes that comprise Master Theme 2 are representative of the devastating sense of powerlessness that a sudden death can evoke and the struggle that ensues to regain some control. It is likely that the

overwhelming lack of control experienced when their loved ones were taken away from them so suddenly leaves them feeling angry, exposed and vulnerable so the participants would feel motivated to reduce these intense emotions by asserting their power where they can. This seems to be achieved through establishing high expectations of others and taking on a punitive, self-critical voice. These attempts to regain control act to isolate the participants from others and increase engagement in maladaptive coping behaviours such as negating their emotions, avoidance and prioritising others over self, which form the focus of Master Theme 3.

3.5 MASTER THEME 3: THE DOUBLE EDGED SWORD OF COPING BEHAVIOURS

This group of sub-themes highlights the darker side of coping behaviours. The sub-themes represent the participants' experience of acting in a certain way or engaging in activities, in response to the obligation to cope. The sub-themes refer to the different behaviours engaged in that mask or avoid their true emotions: by negating emotional expression by locking them inside, by escaping from thoughts and feelings through avoidance activities and by prioritising others over themselves.

3.5.1 'Locked Inside': Negating emotions

Three of the participants refer to having 'locked inside' or 'switched off' their emotions despite seeming to hold an awareness that it is something they do that has adverse effects on their wellbeing in the long term. This struggle is

illustrated by Lorraine as she acknowledges the implications of leaving her emotions locked inside:

“I know that I’d got stuck over [sister] so when it came to [husband] dying, I had in my mind that I didn’t want to get stuck because I know also that you have to grieve because if you leave it locked inside you’ll pay for it in some way, it’ll come back and bite you somewhere”.
(Lorraine, lines 237-240)

In this extract, Lorraine identifies the release and expression of emotion as an essential part of the grieving process, the prevention of which she sees will have negative repercussions including getting stuck. However, she appears conflicted about this as she also describes a time where there seems to be no choice but to lock feelings inside:

“I got through it but only by steeling myself, have to sort of, you have to sort of switch yourself off from... compartmentalise yourself [] And that was how I got through it.” (Lorraine, lines 572-576)

The three different ways that Lorraine uses to describe how she gets through an emotional experience share a sense of numbing and detachment from reality, and the crescendo of similar terms seem to embody the hard work required to protect her from connecting emotionally. This is another way the participants attempt to regain control and feel strong in a context where they feel otherwise powerless. Jenny is explicit about the conflict, identified in Lorraine’s extracts, between the obligation felt to negate

emotions despite understanding the negative effect of locking emotions inside:

“So, you think ‘I’d better not cry’ but if you don’t cry you get more stuck, or that’s what I think. I mean I do think its better to let it out, better to let it out at an appropriate time and I’m not always very good at that”
(Jenny, lines 715-717)

This extract reveals the tension experienced by Jenny when emotions surface as it appears that while she feels an obligation to rationally evaluate whether emotional expression is appropriate in each situation, she finds it difficult to achieve this. The use of ‘*appropriate*’ here seems to cast a shadow over the efficacy of Jenny’s phrase that it’s better to let it out, as it places a caveat on emotional expression and demands logical reasoning. Conversely, Sandra appears to take a great deal of pride in her ability to switch off:

“I learnt how to... you know, because when you think of something, it leads to something. I’ve learnt to switch off now, and think right, work... once work’s finished you’ll go to sleep and then I’m quite good. I’ve trained myself, to say “Right, Goodnight” to shout at myself “Goodnight!”
(Sandra, lines 560-563)

Sandra views her ability to switch off from her thoughts as a resounding success and the punitive voice that has little tolerance and shouts ‘*goodnight!*’ seems resonant of the obligation felt to ‘get on with it’. The

phrases: *'I'm quite good'* and *'I've trained myself'* are evocative of Sandra's pride in her attempts to avoid rumination in the face of adversity.

This sub-theme represents the urge that the participants have to switch off their emotions with the aim of meeting the strongly felt obligation to cope better. A tension is apparent where despite an understanding that emotional expression can help to prevent feeling stuck, an obligation to assess the appropriateness of that expression pervades. The resultant negation of emotions can also leave the participants with an impression that they have taken back some control from their otherwise powerless and weakened position, and so can become a desirable reaction to difficult thoughts and emotions. It appears that negating emotions is a double-edged sword for participants, as although it enables them to get through a difficult experience and provides them with a sense of control, there is an understanding that prolonged locking inside can lead to feeling stuck. The next sub-theme describes a similar double-edged sword where the participants tend to avoid and use distraction as a temporary source of relief from grieving.

3.5.2 'Like Worzel Gummage': Avoidance as relief

This sub-theme describes the pull that the participants feel towards wanting to escape the constant thoughts and emotions in grief through distraction and avoidance. The title of the sub-theme has been taken from Sandra's desire to be able to relieve the incessant thoughts by switching heads like Worzel Gummage, a television character who had three different heads for different functions:

“In my head, if I could just... get a new one (laughs) [] Make life much easier... [] Yeah, like Worzel Gummage, you remember...change the heads. [] Do you know what I mean? Would be so much easier.”
(Sandra, lines 409-415)

Sandra’s repetition of ‘much easier’ conveys how difficult she must find the constant invasion of thoughts where her ideal solution is a fictional escape, which leaves her grief behind. Intriguingly, it is not just the content of this extract that is representative of Sandra’s avoidance, as there is a flippancy through her use of humour, that dismisses the true pain of grief and is reflective of the very avoidance that she covets in Worzel Gummage. Jenny recalls a visit to a cranial sacral therapist who observed her desire to escape reality:

“I had a really strange experience of lying down, and everything spiraling up and away. And she said... she said ‘its like you don’t want to be here’, and that’s been a bit how the grief thing is. Like I don’t want to... be in this world.” (Jenny, lines 417-420)

Jenny’s desire to not be in this world represents a profound and consuming form of avoidance. Confronting reality is too painful for Jenny and leaving this world has an overwhelming appeal. Lorraine reflects on how avoidance and keeping busy represents a double-edged sword for her:

“Cos I find that ... well, [Cruse volunteer] says it’s my strength and my weakness, sort of like a double-edged sword, is the fact that she says I’m strong and erm I get on with things [] Erm, I’m blessed in so many ways, erm and I think you’ve just got to get on with it and I think that was...really where I was concerned that I would get stuck” (Lorraine, lines 374-379)

Like the previous sub-theme of locking emotions inside, avoidance through distraction has a temporary positive effect but can have repercussions if this is the dominant focus of activity. Where Sandra uses humour to dismiss and avoid re-experiencing the true pain of grief, Lorraine seems to dismiss her right to grieve through her belief that she should be grateful for what she has: *‘I’m blessed in so many ways’*. This would likely be experienced in direct conflict with the part of Lorraine that feels she has lost the centre of her universe, and that avoiding and distracting her true feelings would lead to getting stuck in her grief. Conversely, Mabel and Sandra celebrate their distraction techniques and feel the relief as a rest from the thoughts:

“It’s just marvelous, absolutely marvelous. It doesn’t matter what the weather is, I walk and its wonderful because my poor little mind actually has a rest. [] It really does, and its amazing” (Mabel, lines 382-386)

Mabel views distraction by walking as an essential coping mechanism that offers some respite from the otherwise incessant painful thoughts. The use of *‘marvelous’* and *‘amazing’* stand out in the transcript as uniquely upbeat and convey the significance of the relief experienced by Mabel. Unlike

Mabel, Sandra has to work hard to manufacture distractions, and interprets an episode of depression as a personal failure to create enough diversion from the thoughts:

“I put my Ipod on, or I’ll take a book with me. Some sort of distraction... ‘ooh look they’re nice flowers, I wonder what them flowers are’. Lots of distraction. I’ve trained my brain... to distract. [] Which is quite good. [] Done it all on my own (laughs) Do you know what I mean, I’ve trained it to behave. [] Certain things, as I say... sometimes it beats me, and I get very pissed off when it beats me. And this is when I get quite low and depressed” (Sandra, lines 582-595)

Sandra has developed a system of distractions that she believes keeps her safe from depression. Her description of how she trained her brain and that it beats her sometimes is as if she imagines her grief and pain to exist in a distinct and separate part of herself, and fears its potential to overpower her and leave her depressed. It would appear that Sandra has linked periods of depression with a failure to sustain high levels of avoidance, and as such has become increasingly dependent on distraction implied by her delight in successfully training herself. However, this seems to have contributed to a fear of experiencing any grief-related thoughts and feelings and leaves her vulnerable to depression.

This sub-theme refers to the distractions and avoidant strategies that the participants seek out or fantasise about to provide them with relief from their painful thoughts. The extent to which the participants depend on avoidance

to cope varies according to whether they acknowledge the potential for a negative effect and see it as a double-edged sword. It seems likely that the more relief they experience from being avoidant or using distraction, the more fear they feel about experiencing any grief emotions. Although this sub-theme shares similarities with the previous sub-theme of 'locked inside', it is also distinct as '*locked inside*' refers to efforts made to hold back emotional expression, and avoidance refers to efforts made to block out the thoughts and feelings. The third sub-theme introduces another double-edged sword of coping, where the participants prioritise others over themselves, which tends to leave them increasingly isolated and vulnerable.

3.5.3 Prioritising others over self

This sub-theme refers to the participants' urge to protect others from their own grief and emotion so they hide their true pain. Prioritising others over self can become a double-edged sword as although it does protect the others from hurt, it leaves the individual's needs unmet and vulnerable to feeling low with unresolved and unacknowledged pain. For example, Jenny describes her difficulty in accepting that her self-care is integral to her ability to care for others:

"Ok, for me...for me it's been a split between... I mean there is a bit of a split between... looking after yourself and looking after other people or being there for other people. And I suppose I've got, for some reason, I tend to see them as being separate things which I know they're not because obviously if I'm feeling better then I'm better for other people,

but I find that's an awkward area for me. So I suppose that's a sort of stuckness, isn't it?" (Jenny, lines 554-560)

It seems that the knowledge that her wellbeing is an important element in her care for others doesn't help her to take care of herself, and the experience of dissonance between her thoughts and actions leaves her feeling stuck. Like Jenny after the death of her husband, Sandra had children to look after following the death of her sister and describes where her grief came in the list of priorities:

"And I was like, again, push my feelings away from how I felt about my sister going. I was concentrating on these children, these children need me... I haven't got time to grieve, I haven't got time to... you know, I've got to house them, I've got to get new schools..dur dur dur dur. I've got to sort a funeral out, cos I've no parents to... I've got all this to sort out."
(Sandra, lines 232-237)

The language that Sandra uses here seems to highlight the burden of responsibility that she feels for her nephews care when her sister died – the frantic list of activities she has to face, and the resentful reminders that she is all alone without her parents to help her. The phrase 'push my feelings away' links this sub-theme with both the previous sub-themes of negating emotions and avoidance. It seems that she acknowledges that she should give some time to grieving the loss of her only sibling, but sees no room for herself buried under all the needs of others around her. It also links with Sandra's tendency to avoid experiencing her emotions which was explored

in the previous sub-theme. Lorraine views her expression of grief as a burden for her children, thereby prioritising their feelings over her own:

“I don’t say an awful lot. [] No, no, I don’t tell them, erm because I don’t want to worry them, I don’t want to upset them. Erm, I think they’re working through their own stuff” (Lorraine, lines 442-445)

Lorraine’s instinct to protect her children from the pain she is experiencing is echoed in Sandra and Jenny’s experience, and seems understandable as mothers in their established roles of primary caregivers. Prioritising others in order to protect them from pain is behaviour that resonates with both the previous sub-themes of avoidance and locking emotions inside. The sub-theme also highlights the significance of their pain as the participants go to great lengths to protect their family from the potentially harmful experience.

Master Theme 3 Summary

These three sub-themes are linked because they represent the double-edged sword of coping behaviours. By engaging in locking inside, avoiding and prioritising others’ care over self-care, the participants hope to gain relief from both the incessant painful thoughts and feelings and the pressure they feel to abide by the unspoken rules of grieving. In most cases, the relief seems to have proved seductive, but an overdependence on these behaviours to manage their grief has likely contributed to their depression, isolation and feeling stuck. The fourth and final cluster of sub-themes evoke various characteristics associated with the concept of purgatory, which is

interpreted as the consequence of the unresolved conflict explored in previous themes.

3.6. MASTER THEME 4: LIVING IN PURGATORY

This final Master Theme completes the analysis and is comprised of three sub-themes that describe the purgatorial consequences of the unresolved internal conflict they experience. The three previous Master Themes have described the tensions between attempts to regain control and taking responsibility whilst feeling powerless and eclipsed and engaging in coping behaviours that provide temporary relief yet leave them increasingly isolated and stuck. This last theme focuses on the existential fears and feelings associated with the resultant feelings of being stuck. Purgatory is defined as 'a place or state of temporary suffering or expiation' and it is the foreboding sense of waiting in a punishing in-between world that is so evocative of the emergent sub-themes in Master Theme 4. The three sub-themes are: Impending Doom; Loneliness; and 'The same puzzle over and over again': Stagnant.

3.6.1 Impending doom

This sub-theme captures the enormity and destabilising effect of losing such an idealised figure, explored in the first sub-theme, where an inevitable impending doom looms over the participants. While the sense of danger is shared, the participants perceive the threat differently as either a fear that they will bring harm to someone else or that they will be harmed in some

way and that they will die. Sandra experiences this sense of foreboding as a fear for others' safety when in her company:

"Do you know what I mean, I just really do just get stuck. I think, right who's next. And I find it really hard to get close to people, because I think if you get close to me, you know, something might happen".

(Sandra, lines 300-304)

Sandra views herself as somehow the source of the deaths in her family, as if she is cursed and is understandably reluctant to form close relationships. The chilling fear conveyed here that she may unintentionally harm someone isolates her from any potential support and is evocative of the sense of being powerful yet powerless described in Master Theme 2. She goes on to acknowledge her greatest fear of dying before her son is old enough to take care of himself:

"That's my biggest fear. Do you know what I mean, everyday it's...I say to myself, do you know what I mean, let me live [] until he's 18. Because if it's my time to come, please just let me wait until he's 18 so I know he'll be alright (cries)". (Sandra, lines 311-314)

The distress that this causes Sandra is obvious from her emotional response and her use of repetition in her pleading, which arouses a sense of heightened anxiety and urgency. In contrast to Sandra's greatest fear about dying, Mabel appears to be startlingly resigned to her impending doom:

“I sometimes... I wake up, and I think I’m waiting for something, you’ve got that feeling you’re waiting for something and it occurred to me that I’m just waiting to die”. (Mabel, lines 200-202)

Mabel’s phrase ‘*I’m just waiting to die*’ is shocking with its directness and gravity implying that waiting to die is all there is to her life now. Mabel verbalises her existential meaning-making processes, the outcome of which she seems resigned. This type of existential thinking is also evidenced in Jenny’s transcript, when confronted with the minutiae of life as a mother of four children:

“I think that’s more difficult now because you think what’s the point, we’re all going to die.” (Jenny, lines 918-919)

Jenny seems to be struggling to find meaning in life having been in such close proximity with death and therefore has little tolerance for engagement in seemingly meaningless tasks. The cold, matter-of-fact tone of the extract seems to reflect the pointlessness that Jenny experiences. There is a sense of foreboding about Lorraine’s description of the unpredictability of grief:

“I don’t how I’ll feel. It’s so difficult to predict how you’ll feel. Things that you don’t think are going to get you, do and it is like a knife wound.” (Lorraine, lines 470-472)

Lorraine's comparison of the pain she has experienced to a knife wound is a powerful metaphor that helps to explain the fear she feels about how she will be affected by future events. This sub-theme has highlighted the sense of imminent danger, to themselves or their loved ones, which the participants have to live with on a daily basis. The next sub-theme describes the sense of isolation that the participants experience in their grief, magnified by the fear of harming or burdening others and the distancing effect of the pointlessness they feel.

3.6.2 Loneliness

This sub-theme describes the isolation and loneliness the participants have experienced since their bereavement. This is primarily loneliness expressed as a consequence of the loss of their companion, but also the isolation they feel in their grief and as a result of distancing from others. When Mabel describes how alone she feels, there is a sense of despair and hopelessness about her isolation from others:

“It is scary because there's nothing there. There's nobody. I've got no one” (Mabel, line 196)

The sense of utter desolation experienced by Mabel is conveyed through the repetitious listing of '*nothing*', '*nobody*' and '*no one*'. Specifically, her use of '*nothing*' seems indicative that Mabel is not just reeling from the loss of her mother but the loss of her faith in existence where nothing has any meaning.

When Sandra lost her mother, she remembers feeling lonely despite being surrounded by other family:

“I did feel alone, yes. Because my sister had a husband then, She was married. [] So she had her support, do you know what I mean...support, she had someone to talk to. I felt, as I say I was on my own at that time, and I felt, yeah very alone, very alone. Yes, when it was like going to say goodbye to her, switching the machines off, I felt very alone then because everyone had a partner, someone to hug. (Sandra, lines 724-731)

Sandra's repetition of the word 'alone' emphasises the sense of desolation experienced, and the description of being the only person without someone to hug at her mother's deathbed evokes a profound sadness. Jenny also refers to this deeply uncomfortable paradox of feeling alone in company:

“So there are times when I've learnt to be ok on my own, but I don't want to go out” (Jenny, lines 422-423)

The discomfort that Jenny experiences from feeling alone when with others has had a compounding isolating impact as she chooses to avoid socialising. This sub-theme has highlighted the participants' loss of faith in existence and the desperation, sadness and resentment that they experience as a result. The sub-last theme describes the repetitive and frustrating nature of seeking meaning since their loss without success with a resultant stagnancy.

3.6.3 'Doing the same puzzle over and over again': Stagnant

This sub-theme relates to the participants' experience that their grief never changes and they feel that despite efforts to resolve the 'puzzle' in their mind, they remain in a state of ambivalence. This seems likely to result from the internal conflicts identified in previous sub-themes such as attempting to regain control and yet feeling powerless; and feeling eclipsed by the deceased but at the same time holding a responsibility for representing their loved one with a sense of entitlement. The puzzle metaphor used for the sub-theme title was used by Sandra to describe her experience of feeling stuck:

"And this is what... a problem a lot of people like myself as we'll get stuck because we either do the same puzzle over and over again, or be looking for another... you know.. bits of puzzle you know pieces and that's when you get stuck." (Sandra, lines 374-377)

Sandra first used the puzzle metaphor in the interview to describe how people *should* grieve: by doing the puzzle, close the box and then put it away, but her experience of grieving has been very different. Puzzling is likely to represent her attempts to find meaning and resolve internal conflict, but repeated failure to do so seems to have left her feeling impotent in a 'Groundhog Day'-like experience of looking to the past for answers that never appear. Jenny shares this experience of stuckness:

“So I suppose that’s a sort of stuckness, isn’t it? [] And you sort of go over the same...some of the same things.” (Jenny, lines 560-562)

Like Sandra, Jenny identifies that rumination leaves her feeling stuck in the same thought patterns and this extract evokes a sense of resignation to the situation. Mabel’s experience of feeling stuck shares the sense of stagnancy of Jenny and Sandra where every day feels the same, but her frustration is more pronounced:

“I just can’t move forward, I never feel better, I never have a good day, I feel just as bad now as when she died.” (Mabel, lines 220-221)

This extract communicates the extent of the despair and anger that Mabel’s experience of feeling stuck in grief has provoked. There is something so finite about Mabel’s repetition of ‘*never*’ and the absence of any sense of hope is evocative of the impending doom explored in a previous sub-theme. Lorraine experiences her stagnancy as having to overcome relentless hurdles:

“It just seems every time you face a hurdle, you get over that hurdle and then there’s another one [] Just coming up behind it, you know?” (Lorraine, lines 581-584)

This extract represents a peculiar paradox where there is both a sense of monotony and tedium about repeated actions, and yet there is also a sense of escalating dread. It is likely that the monotony of repeatedly encountering

and overcoming obstacles induces a predictability about her situation which develops into a sense of foreboding.

This final sub-theme of stagnancy is analogous with the depiction of *Living in Purgatory*, but despite repeated, desperate attempts to resolve their internal conflicts and find meanings, the participants remain in punishing ambivalence. The tension between being powerful and feeling powerlessness re-emerges in this sub-theme as the puzzling and hurdling are examples of active meaning-making and yet the resultant stagnancy confirms to them that they are powerless.

Master Theme 4 Summary

This fourth and final cluster of sub-themes symbolises the potential consequences of the participants' ambivalence. The *Impending doom* is experienced almost as if a curse, where they fear their potential to harm others or fear being harmed or dying. The sub-theme conveyed the participants' loss of faith in existence, and like the subsequent sub-theme *Alone*, it conveyed their desperation, isolation, resignation and resentment that they experience as a result. The final sub-theme of '*Doing the same puzzle over and over again*': *Stagnant* reveals a cruel paradox where repeated attempts to take control of their life and overcome internal conflicts and obstacles leave them reminded of how they are powerless and stuck.

Analysis Summary

The analysis has been presented in this specific sequence as each sub-theme is seen to be both distinctive in the emergent narrative of feeling stuck in grief and integral to the preceding and subsequent themes that they sit between. Each master theme is an essential component in understanding the overall experience of feeling stuck in grief, but individually or out of sequence they would not tell the whole story. It is the specific sequencing and the way in which they work in synergy with each other that tells this story of feeling stuck in grief. The structure of the themes therefore represents the complexity of, and paradoxes inherent within, the grieving process when it remains unresolved.

Master Theme 1 introduces the participants' understanding of their loss of a loved one as impacting on their sense of themselves and capacity to engage with the world without the deceased person. It highlights their ongoing experience of enmeshment with an idealised but lost other. Participants describe their own life as diminished by the loss and feel dismembered, necessitating investment in keeping the memory of the other alive, which in turn paradoxically serves to further negate their own self and life.

Master Theme 2 builds on the sense of fragility and powerlessness from feeling eclipsed and focuses on the struggle that ensues to regain some control. It seems likely that intense emotions such as anger, feeling exposed and vulnerable are experienced when powerless, and in order to

reduce the distress the participants redress the power imbalance where they can. The transcripts revealed two main ways that they do this: through establishing high expectations of others and taking on a punitive, self-critical voice.

Master Theme 3 describes the maladaptive coping behaviours of negating emotions, avoidance and prioritising others over self that result from the attempts to regain control. These behaviours represent a double-edged sword for the participants as the desire to feel relief from both the incessant painful thoughts and feelings and the pressure to abide by the covert rules of grieving proves seductive, but an overdependence on these behaviours has likely contributed to their depression, isolation and feeling stuck.

Master Theme 4 is the final cluster of sub-themes and represents the consequences of the tension and conflicts experienced by participants that have been identified in the previous themes. The sub-themes emerging here evoke aspects of *Living in Purgatory*, including a sense of impending doom as if they have been cursed, existential loneliness and stagnancy where the monotony of rumination or overcoming relentless hurdles is dreaded. The three sub-themes convey the participants' loss of faith in existence and are intrinsically linked with the enveloping sense of being eclipsed and feeling of powerlessness that pervades the transcripts.

Chapter Four

Discussion

4.1 Overview

This chapter consolidates the information presented in the previous chapters by considering the results in relation to the existing research literature summarised in Chapter One. The Discussion will also draw on additional research that does not feature in the Literature Review, reflecting the inductive nature of Interpretative Phenomenological Analysis (IPA) and the expectation that the interviews and analysis will transport the researcher into “new and unanticipated territory” (Smith et al, 2009, p.113).

Semi-structured interviews were conducted with four female participants who had approached Cruse Bereavement Care for support with their experiences of feeling stuck in grief. An interview schedule was designed to address the following research questions: (1) What are the meanings and constructions underlying narratives on feeling stuck in the grieving process? (2) What is the nature of the interplay between grief experience and expectations about grief? (3) What is the nature of the interplay between feelings of being stuck and the responses from family members and friends to these feelings of being stuck and to the event of loss itself?

Much of the content of the themes that have emerged from this study have been explored in the existing literature: engagement in avoidance as a response to the internal conflict (Shear, 2010), motivation to reduce

cognitive dissonance (Festinger, 1962), the struggle to find significance in the loss is particularly acute following deaths that are traumatic (Gillies & Neimeyer, 2006). However, this study's results reveal a novel insight into the experience of feeling stuck in grief and provide a fresh perspective from which to approach therapeutic interventions. The results reveal both the significance of living with unresolved dilemmas of grieving, and the consequences; being stuck in a vicious cycle of fear and avoidance and feeling a sense of impending doom, loneliness and stagnancy. A departure from traditional stage-based approaches is encouraged for those who provide therapeutic support to bereaved individuals experiencing 'stuckness' and suggestions for tailored interventions are explored. These include CBT-derived cognitive restructuring to identify and challenge maladaptive cognitions and exposure therapy to reduce dependency on avoidant behaviours. The chapter concludes on a proposal for possible avenues for future research.

4.2 Understanding the emergent themes in the context of existing grief literature

The following section explores how the emergent themes from this study are represented in the existing literature, and how the results expand on the current conceptualisation of the phenomena. These include an exploration of the unresolved dilemmas of grieving; the zero sum game and the powerful powerless; being stuck in a vicious cycle and the purgatorial consequences of living with ambivalence.

4.2.1 The unresolved dilemmas of grieving

Within the literature, a conflict has developed between the drive to delineate 'normal' grief (Prigerson et al, 2008; Shear et al, 2011) and the acknowledgement of the uniqueness of grief experience (Lang & Caplan, 1993; Worden, 2009). It seems that this fundamental paradox identified within the grief literature (Breen & O'Connor, 2007) is mirrored in the paradox-rich experience of feeling stuck in grief. One of the most striking findings to emerge from the current research is the accumulation of conflict and dissonance that contributes to this experience. Some are explicitly described by the participants, for example the obligation to negate feelings and avoid emotional triggers despite the acknowledgement by two of them that this inevitably causes them to become more stuck. Other paradoxes remain unrecognized by the participants, for example feeling increasingly overwhelmed by the responsibility to grieve for such a deified figure, yet only acknowledging an idealised version of the deceased. The extract chosen for the title of this thesis: *"Doing the same puzzle over and over again"* (Sandra, line 375) is interpreted as symbolic of the repetitive, yet unsuccessful, attempts to resolve the paradoxes revealed in the data analysis.

The existence of painful dilemmas in grief is not a new concept, nor is the engagement in coping behaviours such as avoidance as a dynamic and adaptive response to the internal conflict (Shear, 2010). Bowlby (1980) refers to the conflicting experience of people with complicated grief who are kept prisoner by an unresolved dilemma:

"So long as he does not believe that his loss is irretrievable, a mourner

is given hope and feels impelled to action; yet that leads to all the anxiety and pain of frustrated effort. The alternative, that he believes his loss is permanent, may be more realistic; yet at first it is altogether too painful and perhaps terrifying to dwell on for long.” (Bowlby, 1980, p.139)

However, grief literature has not explored the two major paradoxes revealed in the participant accounts of the current study and their role in ‘stuckness’ in grief. The first is the experience of reeling under the responsibility of representing the deceased and ultimately feeling eclipsed and yet maintaining that perceived pressure through idealization; the second is making attempts to regain control, despite holding a perception of themselves as being entirely powerless.

i) The zero sum game.

The results reveal a shared sense of devotion for, and dependency on, the deceased to the extent that their pre-bereavement lives seemed wholly integrated. There is an exclusivity about the relationships described where the participants seem to hold a sense of entitlement for their grief of such esteemed love and describe the overwhelming sense of responsibility to honour the idealised relationship. These descriptions of intense and dependent relationships are characteristic of Prigerson’s (2004) description of the type of relationship and person that has the highest risk of complicated grief. Relationships that are close, confiding and dependent are thought to be a risk factor for complicated grief, as are people who tend to be *“glued together by the presence and support of the deceased person and who find themselves correspondingly torn apart by their absence”*

(Prigerson, 2004, p39).

In the current study, the participants appear to have difficulty in the process of individuation and separation, evidenced by the idealisation and the sense that their lives were almost extinguished following the death of their loved one. The participants described the loss as physical pain within their own body and three of them compared the loss to an amputation, as if their two bodies operated as one until the death. Research that links insecure attachment styles and separation anxiety developed in childhood with complicated grief reactions (Van Doorn, Kasl, Beery, Jacobs, Prigerson, 1998; Vanderwerker, Jacobs, Parkes & Prigerson, 2006) may help to explain the difficulties experienced by the participants.

Elevating the deceased to such a deified representation becomes a zero sum game for the participants, as the more they attribute parts of themselves to the deceased and the more they idealise their loved one, the more significant their responsibility becomes to grieve accordingly and the less resources they have to cope. This appears to be an example of polarised thinking which acts to maintain an idealised conceptualisation of the deceased, to which they compare all other people and relationships. There is a stark contrast, evidenced in the transcripts, between the discernable qualities attributed to the deceased and the experience of others not understanding their situation well enough, not listening properly, not caring enough and not measuring up to the deceased. It has been suggested that this tendency to blame others can form an obstacle to adapting to negative life events (Garnefski et al., 2002) which may offer an

insight into how people get stuck and is therefore an important issue to explore in grief therapy.

This all or nothing thinking is identified by Fourali (2000) as one of the most problematic cognitive distortions and can be very difficult for emotionally distressed individuals to attend to, let alone understand how it contributes to their distress and challenge it (Fourali, 2009). Therapeutic interventions that focus on psycho-education about polarised thinking and the promotion of a more realistic and balanced perspective, where both positives and negatives of the deceased and others are explored, would facilitate adaptation to the loss. A less polarised view of the deceased may also act to reduce the eclipsing effect on resources evidenced in the participant accounts, and provide opportunities to integrate the loss, reduce expectations of others and accept support.

ii) The powerful powerless

The second paradox emerging from this study is that of the participants perceiving themselves in a powerless, vulnerable position where they feel a lack of any control over their lives, and yet making clear attempts to regain control including establishing high expectations of others and by taking on a punitive, self-critical voice. This acts to unintentionally isolate themselves from others and increases engagement in maladaptive coping behaviours such as negating their emotions, avoidance and prioritising others over self.

In terms of the research questions, the sub-theme of *Feeling obliged to 'get*

on with it' captures the dissonance between the expectations and the realities of grief experience. Cognitive Dissonance Theory (Festinger, 1962) states that if a person holds two dissonant cognitions, the discomfort derived from the dissonance is motivation to reduce it and the magnitude of dissonance experienced is dependent on the number and importance of cognitions. The reduction of dissonance can be achieved by a change in behaviour, a change in attitude, addition of elements consonant with behaviour or a change in the perceived importance of either cognition. (Shaver, 1987). The current research reveals several implicit social norms or rules of grieving that appear to have been internalised in the participants' conceptualisation of grief. These include that they should feel better over time, they should be able to cope by now, they shouldn't burden others with their grief, emotional expression is not tolerated, and they should leave the past behind and live for today. The findings confirm previous research that rules of grieving are widely known and recognised but rarely stated explicitly. Harris (2010) notes that the oppressive factor of shame and the inhibition caused by expectations of how we should grieve in Western society has the potential to suppress adaptive responses.

The data in the current study revealed that the participants experienced a sense of failure when their behaviour contradicts these rules. It is an assumption of Cognitive Dissonance theory that dissonance is an unpleasant state of mind and, congruent with cognitive consistency theory, it is human nature to behave in ways that minimize or avoid the internal inconsistency (Shaver, 1987). In accordance with this theory, it is likely that the participants experience dissonance between their subjective experience

of grief and their expectations, the internalised rules, and so in an effort to reduce it they attempt to bring their behaviour in line with their expectations. As a result they use self-punishing mantras such as '*get on with it*', '*grin and bear it*', and '*pull yourself together*' to encourage social conformity and they engage in avoidant coping behaviours. Silver & Wortman (2007) assert that if bereaved individuals hold rigid grief expectations, their bereavement-related distress may be exacerbated as they feel that they are not coping and become self-critical of their 'inappropriate' grief response. Costa, Hall & Stewart (2007) cite several studies that confirm the persistence of traditional stage model assumptions that characterise the grief-related expectations held by individuals, and caution that this can result in a lack of adequate support.

These results suggest that there is an element of feeling stuck in grief that derives from the dissonance between the internalised rigid, stage-based expectations of grieving and the unique, painful and unpredictable grief that the participants experience. However, it is apparent from the other emergent themes that this is not the only internal conflict that the participants experience and that there are other contributing factors in the participants' experience of feeling stuck in grief.

4.2.2 Stuck in a vicious cycle

The results in Master Theme 3 reveal a double-edged sword effect of coping behaviours where the participants engage in negating emotions; avoiding, distracting, using humour or pleasing others in order to numb themselves,

detach from reality and reduce the intensity of the painful emotions experienced. Yet the consequences of doing so appear to reinforce the fear of experiencing the pain, thus rendering them stuck in a vicious cycle of fear, heightened emotional response and avoidance. Avoidance of reminders of the realities of the loss is a normal response to grief (Shear, 2010) and has been identified as a key symptom of prolonged grief (Prigerson et al, 2008). When used adaptively, avoidance can be used to avert painful thoughts or feelings related to the loss and restore the capacity for a satisfying life, but if it is over-used as a coping strategy, it impedes the processing of difficult information and prolongs acute grief (Shear, 2010, Worden, 2009).

The results revealed a varied level of understanding about the potential for negative consequences of avoidance, where a low perceived connection with negative consequences reflected a higher level of dependency on avoidant behaviours. Different forms of avoidance were identified in the results of this study: some take considerable effort such as distraction and attempts to negate emotional expression, others such as wishing oneself in another world or longing for escape are more passive. Interestingly, research recognises the first sub-theme of idealising the deceased as a form of avoidance, where the stimulation of solely positive memories is protective from the discomfort of unpleasant thoughts (Worden, 2009), but can act to prevent the person from engaging in satisfying activities and forming new relationships (Shear & Frank, 2006).

Excessive avoidance is thought to become a major impediment to the adjustment to loss and to both loss-oriented and restoration-related

processes according to Stroebe & Schut's (2001) dual process model (Shear et al, 2007). The potential negative implications for becoming stuck that are revealed in the results of the current study are significant, evidenced by Bonanno et al's (2005) research where deliberate avoidance by bereaved spouses at 4 months post-loss predicted poorer perceived health and more psychological distress at 14 months post-loss for both American and Chinese participants.

4.2.3 The Purgatorial consequences of living with ambivalence

Another impactful theme to emerge from this research encapsulates the foreboding sense of waiting in an in-between world, feeling neither alive nor dead, likely to have resulted from the unresolved dilemmas described above. The participants' accounts reveal a struggle to find meaning in life, where they seem to have lost faith in existence. Existing research asserts that the process by which bereaved individuals question and make sense of their loss is central to the experience of grief, but the bereavements that fail to make sense are the most difficult to adjust to (Folkman, 2001) as 'they throw everything that once had meaning into doubt and turmoil' (Gillies & Neimeyer, 2006, p.36).

In line with this research, each of the participants interviewed for the current study were bereaved through a sudden and unexpected death where one perceived the death to be as a result of murder. Gillies & Neimeyer (2006) cite several studies that demonstrate that an inability to find answers to existential questions early in bereavement is a risk factor for less favourable

grief outcomes, and that the struggle to find significance in the loss is particularly acute following deaths that are traumatic or 'off-time' in the life cycle. The current study highlights the subjective experience of that struggle with meaning-making in the themes of *Impending doom*, *Loneliness* and *'Doing the same puzzle over and over again': Stagnant*.

Despite the avoidant coping behaviours providing temporary relief, they feel increasingly isolated and stagnant in Purgatory where they feel they are coming up against the same hurdles again and again, have a sense of impending doom and feel lonely. Although all the participants share the sense of danger, the threat is perceived from different sources: either externally where they feel they are waiting to die or will be harmed somehow; or internally as if they are cursed and could unintentionally harm others.

The repetitive nature of puzzling over the same internal conflict over and over again, or having to overcome obstacle after obstacle introduces a further paradox for the participants. Although there is an iterative or predictable sense to their repetitious experience, it acts to exaggerate the sense of impending doom and inevitability of the profound sadness. Repeated failure to make sense of the loss, despite many attempts to 'puzzle' over it, leaves the participants feeling impotent and reinforces their feelings of powerlessness.

The desolation, sadness and isolation that the participants describe is experienced primarily as a consequence of the loss of the *centre of their*

universe but they also feel isolated as a result of distancing themselves from others. Weiss (1973) differentiates between social and emotional loneliness, where the former refers to a lack of an engaging social network and social embeddedness, and the latter refers to a sense of utter aloneness and isolation for which social support offers no relief. In a study comparing widowed and married older women, social loneliness was experienced at similar levels, but emotional loneliness was significantly higher amongst the widows regardless of social support (Stroebe et al 1996). Van Barse et al (2001) stresses the significance of acknowledging the difference between social and emotional isolation. Worryingly, the impact of emotional loneliness has been largely overlooked in grief literature, despite almost a third of conjugally bereaved individuals showing high levels for years after their bereavement (van der Heuven et al, 2010) and it being found to mediate the impact of marital bereavement on health and well-being (Stroebe, Stroebe & Abakoumkin, 2005). This research helps to contextualise the participants' experience of feeling lonely whilst surrounded by others, and means therapeutic interventions targeting loneliness must go beyond encouraging social support, and should include a focus on continuing bonds (Klass, Silverman & Nickman, 1996) and reintegrating the lost loved one (Van der Houwen et al, 2010).

4.3 Summary of findings

The themes emerging from this research, supported by existing literature cited above, suggest that feeling stuck in grief is a conflict-laden experience which leaves the bereaved individual with a foreboding sense of doom,

stagnancy and emotional loneliness. The *zero sum game* describes the counterproductive effect of polarised thinking such as idealising the deceased, which acts to diminish the life of the bereaved individual. The *powerful powerless* refers to the paradox of reporting that they feel inert and out of control, yet creating the illusion that they are in control. Further conflict was revealed in the transcripts where the participants found themselves *stuck in a vicious cycle* of fearing the pain of grief and engaging in avoidant behaviours. Results suggest that dependency on avoidance varies according to their awareness of the potential harm that continued avoidance can cause to their well being. Finally, the purgatorial consequences of struggling to make sense of the loss were revealed; a persistent sense of danger perceived from either internal or external sources, the emotional loneliness that is not relieved by social support and the interminable necessity to overcome the same hurdles.

So where does this study position itself within the debate about the proposed inclusion of a diagnosis of prolonged/complicated grief in the DSM-V? Having interviewed individuals who would fit the proposed diagnostic criteria for prolonged grief and examined the two sides of the debate, the results demonstrate a clear argument against any further pathologising of grief. Existing research supports the current study's findings that models delineating 'normal' grief appear to increase pressure on vulnerable individuals to engage in maladaptive coping behaviours in attempts to conform to cultural and social norms. However, there is also a strong case for therapeutically treating these individuals who are explicit about the distress they are experiencing, and it could be argued that the DSM-V, being

the main diagnostic tool used by GPs, could improve access to therapeutic support for these individuals. For Counseling Psychologists, the DSM is a common source of debate which remains largely unresolved, nevertheless it is believed that the proposal and the ensuing debate has been very valuable for bereavement research. It has inspired research activity to focus on a very important group of individuals who can be helped by specifically designed therapeutic interventions, explored in the section below, that allow for their unique experience of grief.

4.4 Clinical implications

Recent research into the efficacy of grief therapy reveals that emotional disclosure alone does not facilitate adjustment to loss (Stroebe, W., Schut & Stroebe, 2005) and is more effective when the client self refers (Allumbaugh & Hoyt, 1999), is high-risk (Schut & Stroebe, 2010), experiencing chronic or complicated grief reactions (Jordan & Neimeyer, 2003) or has experienced bereavement through sudden or violent death (Worden, 2009). Although it is true that the participants in this study fit this profile and appear likely to benefit from grief therapy given the evidence supporting a meaning reconstruction conceptualisation of grief (Matthews & Marwit, 2004), the study is based on the experience of four participants and it is therefore not argued that they are necessarily representative. However, the significance of some of the more salient emerging themes is supported in diverse areas of existing grief literature, which is suggestive that the clinical implications are worth considering.

Therapeutic interventions to address the zero sum game of feeling eclipsed, yet continuing to idealise could usefully focus on two main areas: the first to help the client develop a stronger sense of self and the second area to promote a more balanced and less polarised perspective of the deceased and others. All or nothing thinking has been linked with unresolved conflict and so to address the tendency to engage in black and white thinking, a CBT approach would be suggested that encourages the client to consider a more balanced perspective (Fourali, 2009).

The therapist's conceptualisation of grief is of great significance when helping clients who experience dissonance between their lived experience of grief and their expectations of how they should feel. On the basis that internalising a stage-based, time-limited model of grief imposes restrictions on bereaved individuals (Costa, Hall & Stewart, 2007), to the extent that they become self-punishing towards their behaviour, it becomes critical that the therapeutic approach doesn't collude with this perception. Foote & Frank (1999) suggest that therapeutic interventions that are shaped by stage theory act to 'discipline' grief by encouraging conformity to societal norms. This stance in grief therapy is likely to increase dissonance between the client's true grief response and their expectations of that response, where their feelings of ambivalence may be exacerbated and their dependency on maladaptive coping behaviours will continue. An approach is required that both releases the client from their restrictive, internalised model of grief and helps them acknowledge and process their internal conflicts that they have tended to dismiss or avoid in order to adhere to their model. Walter & McCoyd (2009) describe such an approach:

“It is important that clinicians working with people who are grieving recognize that the stories will take multiple forms and the task of the therapist is *not* to force an adherence to a ‘true’ or ‘real’ one. Instead, we are to help the client create his or her own coherent story while assisting in shining new light on the possibilities of blind spots that may enable a story that fits the client’s evolving and dynamic worldview in evermore useful and function-promoting ways” (Walter & McCoyd, 2009, p.15).

Encouraging the client to engage in more self-care and to offer more compassion to themselves would aim to reduce the punishing self-talk that results from the obligation to conform to their perceived norms of grieving.

Shear’s (2010, p13) description of the difficulty in achieving adaptive oscillation between loss and restoration-oriented coping in complicated grief resonates with the findings of the current study:

“loss-focused attention remains intensely painful and infused with deep longing and restoration-focused attention is associated with a sense of disbelief and protest and, in the best of cases, a feeling of resignation that life must go on, though there is little sense of purpose, joy or satisfaction”.

Shear et al (2005) have developed a Complicated Grief Treatment (CGT) to overcome the obstacles to adaptive oscillation between the two types of coping. It is an intervention that is rooted in Attachment Theory and draws from Interpersonal Therapy, Cognitive Behavioural Therapy and Motivation Interviewing, viewing grief as a natural process that can become impeded when a loss fails to be integrated (Shear, 2010). A targeted cognitive behavioural approach, such as that proposed by Boelen et al (2007), will be particularly relevant for clients demonstrating an excessive dependence on avoidance as cognitive restructuring can help to identify and challenge

negative cognitions and exposure therapy can help to confront rather than avoid reminders. Effective therapeutic interventions will need to focus on attending to the various forms of avoidant behaviours, both covert within the therapeutic relationship (e.g. using humour) and explicit within client descriptions of their behaviours as it has been found that grief avoidance is notoriously difficult to bring to light (Shear, 2010). A comparison of CBT strategies in complicated grief showed that exposure is the most effective intervention, perhaps due to its focus on both emotional and behavioural elements (Malkinson, 2010).

Initial results from efficacy studies of CGT have demonstrated twice the rate of improvement in clients compared with those who received a more general form of psychotherapy (Shear et al, 2005), but large drop out rates (42%) by clients who are not taking antidepressants (Simon et al, 2008) have led to criticism as it appears to be a very challenging treatment for this group of clients (Wetherall, 2012). Further research is therefore required before CGT can be recommended for clients who are feeling stuck in grief, but an integrative approach would be advocated that combines the techniques supported by Shear et al's (2005) and Boelen et al's (2007) research with a focus on the therapeutic relationship to help the client develop a stronger sense of self. The therapeutic relationship particularly crucial in this context as clients with an avoidant style have been found to do less well in CBT, but this effect is mediated by the therapeutic relationship (Hardy et al, 2001).

With regards to interventions helping clients to deal with emotional loneliness, as distinct from social loneliness, a focus on continuing bonds and to integrate the loss is recommended (Van der Houwen et al, 2010).

Gillies & Neimeyer (2006) promote grief interventions that help to reshape the client's shattered world, promote new insight and personal growth and guide meaningful actions in response to the loss. Guiding the client to reflect on how the experience has changed them, using narrative exercises (Neimeyer, 1999) and encouraging the client to continue dialogue with the deceased in the form of letters, prayers or meditation has been found to help the client integrate the loss into their lives. This approach to promote healthy continuing bonds is supported by Malkinson, Rubin & Witztum (2006), who view the relationship with the deceased and reworking the bonds as an 'exceedingly important focus' for therapy. They propose a dual focused intervention that aims to both restore coping to be able to deal with the demands of living with a loss, and to help the client manage the memory of the relationship and the loss.

4.5 Reflexivity

One aspect of the research that became particularly challenging in this study, reflected upon in the methodology, was the generation of emotions, for both participant and researcher, and attachments during the interviews which persisted into the analysis phase. Gemignani (2011) highlights the importance of embracing, and reflecting on, countertransference in qualitative interviews when engaging in research that is sensitive in nature or of personal significance. Devereux (1967, cited in Gemignani, 2011) proposed that ignoring the countertransference in research can result in generating data that is less relevant, more segmental and perhaps even trivial.

Like Gemignani (2011), who interviewed refugees from Yugoslavia, I felt a weight of responsibility to help my participants. To detach from the emotions following the interviews felt like abandonment, but I empathise with Gemignani's (2011) reluctance to immerse too deeply initially as if still clinging to scientific objectivism. However, I soon found this a restrictive position and progressed to reflecting on the countertransference in the interviews, which became an increasingly valuable analytical resource. For example, exploring my own feelings of powerlessness as I left the participants' homes helped me to recognize how these resonated with the participants' accounts of struggling to make sense of their experience.

Given the assertion that the research interview is an interaction between two parties (Ripley, 2001), it seems prudent to reflect on the impact that my role as interviewer had on the data collection process. There were times during the interviews when my responses were perhaps more therapeutic than probing, partly to protect the participants from bombardment of questions and partly to help the participant understand their unexplained experiences. For example, I used summarising with Sandra, which in a therapeutic context would communicate to her that I was listening attentively:

Interviewer: So you don't feel in control anymore?

Sandra: Yeah, that's it, it's beaten me for a while.

Sandra was the fourth interview I conducted and I made a conscious decision early on to continue to intersperse some therapeutic conversation in with the interview questions as a way of managing the tension between seeking specific data and the need to engage in the 'here-and-now'

interactional event (Ripley, 2001). I asked the questions from the interview schedule in different sequences with the different participants which allowed the interview to flow naturally and helped the client to explore their experiences more widely.

The questions posed from the interview schedule were all designed to be as open as possible to encourage the participants to sculpt the interview to encompass their unique experience. This was a successful outcome for Mabel, Sandra and Lorraine, but the open questions tended to concern Jenny about whether she had understood them 'correctly'. Reflections in supervision following the interview drew comparisons between her desire to answer 'correctly' and her desire to understand how to grieve 'correctly'. Also discussed in supervision were the examples of questions that lead a participant to use my language, for example with Sandra

Interviewer: That must be...yeah must be... very heavy

Sandra: And sometimes I think because it's quite heavy going, I often dream about them.

I took care not to use these examples from the transcript in the analysis write up as although the participants seemed to identify with the words, it is perhaps a construction that they would not have created themselves. In future research, I would suggest that open questions about the broad topic at the beginning of the interview helps the participant to feel comfortable with the process, and then to introduce more focused questions around the research questions that are open enough to help the participant to communicate their own perspective, but specific enough to ensure the relevance of the collected data.

At times, a parallel process emerged between the participants' experience of feeling stuck and 'doing the same puzzle over and over again' and my own experiences during the research process. As Smith (2010) notes, IPA is a dynamic and iterative process, where previous analysis is regularly revisited to make sense of the unfolding account. Reflective diary entries during the early reading and re-reading phase of analysis capture the challenge to slow down my "propensity for 'quick and dirty' reduction and synopsis" (Smith et al, 2009, p.82) and to painstakingly return with fresh eyes to attend to the descriptive, linguistic and then conceptual aspects of the transcripts. My desire to accelerate that process and to find order amongst the overwhelming amount of material that emerged from analysis was paralyzing at times, and has a striking familiarity with the experience described by the participants to 'get on with it', pull themselves together and to return order to their world.

Each revisit to the transcripts gave rise to a new insight and Sandra's puzzle metaphor is applicable in describing how the shape, number of pieces and imagined solution of my research puzzle was in constant flux. Once the themes had been identified in the analysis, the process of repeated 'puzzling' began again to ensure the themes were relevant, representative and not repetitive. Research supervision helped to overcome my own internal conflicts during this period, arising from the paradox of wanting to represent the uniqueness of the participants' experience, yet wanting to find commonalities from which to construct themes. Regular reflection of these parallel processes being enacted within my research process helped to push

the analysis beyond a descriptive, phenomenological account as doing the same puzzle over and over again and the feeling of being stuck became so pertinent and resonant.

4.6 Critique of the research

In order to assess the quality of the current study, it is proposed to return to Yardley's (2000) guiding principles for quality in qualitative research outlined in Chapter One. The researcher has strived to achieve a high standard of *transparency and coherence* by interweaving reflexivity throughout the methodology and by rooting the research in the underlying principles of IPA. It is phenomenological in approach by focusing on the lived experience of feeling stuck; it is also hermeneutic evidenced by the depth of analysis in Chapter Three that goes beyond a descriptive account, and idiographic through its commitment to the specific and the individual. By allowing the participant a voice, using an interview schedule only as a guide, and grounding the analysis firmly in the verbatim transcripts, it is believed that this research demonstrates *commitment, rigour and sensitivity to context*. Lastly, it is hoped that Yardley's (2000) requirement for *impact and importance* have been achieved in the current study, through the fresh perspective presented on the experiences and consequences of living with the ubiquity of dilemmas in the grief process. The researcher believes that *impact and importance* have also been achieved through the comprehensive addressing of the research questions in the emergent themes: from the inherent paradoxes within the grieving process and being stuck in a vicious cycle of fear and avoidance to the purgatorial consequences of living in

ambivalence.

As discussed in Chapter Two, the richness of the data, the depth of analysis and the novel insight brought to the field of grief research, go some way in mitigating the small sample size in the current research, but the size of the sample does nevertheless represent a limitation. Several of the emergent themes from the analysis may help to explain the challenges experienced in recruiting sufficient participants. It has been suggested that those who are the most vulnerable may choose not to take part in research (Dyregrov, 2004), so when someone feels that no one understands, when avoiding is preferred over confronting and when it is difficult to maintain a faith in existence, there is likely to be a reluctance to engage in a process that may be perceived as critical, uncaring or an ordeal.

In addition to the potential for reluctance to self-refer, the recruitment of the participants depended on a third party to distribute the recruiting leaflets. A concern in this study therefore, shared by researchers studying a parent's grief who have lost a child with a learning disability (Reilly et al, 2008; Todd, 2007), is that service providers were reluctant to distribute leaflets in order to protect their clients from what was perceived as a potentially traumatic experience. Also of note is that the participants are all white, British women who were bereaved as a result of a sudden death. Further research is therefore encouraged that incorporates men's experience of the phenomenon and explores the nature of the experience of feeling stuck in grief outside of the cultural norms of Western society.

Despite the sampling limitations, the strengths of the current research lie in the novel insight into an area of research that is under-represented in the grief literature. Smith, Michie, Stephenson & Quarrell's (2002, p. 132-133) assertion that IPA is "especially useful when the research is concerned with either a novel domain or where the issues are complex or dilemmatic" is suggestive that the choice of methodology in the current study was appropriate for the conflict-laden experiences of feeling stuck in grief. The research also cautions against holding stage-based conceptualisations when supporting bereaved individuals as it can exacerbate the distress felt as a result of internal conflict and can contribute to, rather than reduce, feelings of being stuck in grief.

4.7 Suggestions for future directions in grief research

Firstly, the struggle with conflicting thoughts that has emerged in the results of this research suggests that more knowledge is required about both the impact of living in ambivalence and the interventions that are most effective at helping clients to adjust to their loss. Secondly, the potential risk posed to clients by volunteers and therapists holding stage-based conceptualisations of grief has been highlighted in this research, and therefore finding alternative ways to disseminate contemporary grief research findings into practice should be prioritised, aside from journal articles which have been found to be the least helpful in the practice of service providers (Bridging Work Group, 2005).

Chapter Five

Conclusion

The hermeneutic phenomenological approach taken in this research represents a departure from the enduring legacy of the positivist tradition in bereavement research, and is reflected in the selection of Interpretative Phenomenological Analysis (IPA) as the preferred research methodology. Several areas in contemporary grief theory are represented within this research including the lived experience (Davies, 2004), adaptation to loss (Rothaupt & Becker, 2007; Worden, 2009) and the social and cultural aspects of meaning-making (Park 2010; Stroebe, Hansson, Schut & Stroebe, 2008).

The aims of the study were to give a voice to the subjective experience of individuals who feel stuck in grief by exploring the meanings and constructions underlying narratives on feeling stuck in the grieving process and the interplay between grief experience and the internally and externally sourced expectations about grieving. Semi structured interviews were conducted with four participants who self-referred to a National Bereavement charity as they reported feeling stuck in their grief. Analysis of the interview transcripts produced twelve subordinate themes, summarised into four Master Themes, which together provide new insight on the experience of feeling stuck in grief.

The first Master Theme *Eclipsed by the deceased* illuminates the zero sum game of idealising the deceased, as the more dependent and enmeshed they

become with the deified representation, the less adaptive their coping becomes and the more they fear letting go. The second Master Theme describes the paradox of gaining back control over life in response to feeling vulnerable and powerless. Sub-themes include *Feeling let down by others*, *Feeling out of control* and *Feeling obliged to 'get on with it'*. The obligation to 'get on with it' is derived from cultural norms of grieving, and leaves the participants feeling conflicted between their expectations of how they should feel or behave and the realities of their grief experience. These internal conflicts likely contribute to increases in the engagement in *The Double-edged sword of coping behaviours*, the third Master Theme which captures the avoidant behaviours including: *negating emotions*, *prioritising others over self* and *'Like Worzel Gummage': avoidance as relief*. The fourth and final Master Theme highlights the sense of *impending doom*, *loneliness* and *stagnancy* that embody the purgatorial consequences of living with ambivalence.

Proposals for appropriate therapeutic interventions include CBT interventions such as cognitive restructuring and exposure therapy, which are relevant for clients struggling with unresolved conflicts and engaging in excessive avoidance. The results also suggest that service providers offering grief support should encourage the client to create their own story and avoid encouraging adherence to a stage-based model of grief. Finally, it is proposed that future research focuses on exploring the significance and impact of unresolved conflict in grief and on finding innovative ways to disseminate contemporary models of grief to service providers.

This research supports contemporary meaning-making conceptualisations of grief and draws on the theories that inform the recommended therapeutic interventions such as the Dual Process Model (Stroebe & Schut's, 2001), continuing bonds (Klass, Silverman & Nickman, 1996) and Neimeyer's (2001) meaning reconstruction approach. The research has made distinctive contributions to Counselling Psychology and bereavement research. Firstly, it reveals the significance of unresolved internal conflicts in individuals who feel stuck in grief, secondly it highlights the distressing consequences of living in ambivalence and thirdly, it positions the service providers' conceptualisation of grief as central to the efficacy of future grief interventions.

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APPENDIX I

Ethics Approval – Cruse Head Office

Print <http://uk.mg.bt.mail.yahoo.com/neo/launch?partner=bt-1&rand>

Subject: RE: Research Proposal – Lucy Poxon

From: Catherine Betley (Catherine.Betley@cruse.org.uk)

To: lucy.poxon@btinternet.com;

Date: Tuesday, 2 August 2011, 10:41

Hello Lucy,

I'm sorry it has taken me so long to get back to you.

I am happy to confirm that your proposal has been reviewed, commented on and approved by myself on behalf of Cruse Bereavement Care (the national organisation) and we very much look forward to seeing how the work progresses. I am pleased that the local branch is able to support your research.

All good wishes,

Catherine.

Catherine Betley
Director of Services
Cruse Bereavement Care

Tel: 01524 782910
Mobile: 07951 348174

Ethics Approval – Cruse Local Office

Print <http://uk.mg.bt.mail.yahoo.com/nco/launch?partner=bt-1&rand>

Subject: Research

From: Cruse Office (cruseoffice@talktalkbusiness.net)

To: lucy.poxon@btinternet.com;

Date: Monday, 25 July 2011, 17:40

Dear Lucy

I write to confirm that the management team at Ashford branch of Cruse Bereavement Care has approved your research proposal and agreed that you may go ahead with it.

many thanks and good wishes
Shirley Leslie
Acting Administrator

Ethics Approval – UEL

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MISS LUCY POXON
FAR END
OTTERDEN CORNER
STALISFIELD, FAVERSHAM
KENT
ME13 0BS

Date: 5 August 2011

Dear Lucy,

Project Title:	A Qualitative Exploration into Bereaved Clients' Feelings of 'Stuckness' in their Grieving Process
Researcher(s):	Lucy Poxon
Supervisor(s):	Aneta Tunariu

I am writing to confirm that the review panel appointed to your application have now granted ethical approval to your research project on behalf of University Research Ethics Committee (UREC).

Should any significant adverse events or considerable changes occur in connection with this research project that may consequently alter relevant ethical considerations, this must be reported immediately to UREC. Subsequent to such changes an Ethical Amendment Form should be completed and submitted to UREC.

Approval is given on the understanding that the 'UEL Code of Good Practice in Research' (www.uel.ac.uk/qa/manual/documents/codeofgoodpracticeinresearch.doc) is adhered to.

Yours sincerely,

Merlin Harries
University Research Ethics Committee (UREC)
Quality Assurance and Enhancement
Telephone: 0208-223-2009
Email: m.harries@uel.ac.uk

Docklands Campus, University Way, London E16 2RD
Tel: +44 (0)20 8223 3322 Fax: +44 (0)20 8223 3394 MINICOM 020 8223 2853
Email: r.carter@uel.ac.uk



APPENDIX II

Recruiting leaflet for Cruse Volunteer Supporters



Dear Cruse Volunteer,

Call for research participants - can you help?

I am a Cruse volunteer with Ashford Cruse Bereavement Care and a trainee Counselling Psychologist at the University of East London. I am conducting research into feelings of 'stuckness' in the grieving process and to explore the role of cultural norms, expectations and the family.

I am looking to interview clients who fit the following criteria:

- Has completed the first session with Cruse volunteer
- Aged over 18
- Has been bereaved over 6 months

If you think you have client(s) who fit these criteria, and you feel that they would be able to speak about their experiences of their grief, I would be very grateful if you would give them one of the advertising leaflets attached.

All personal details will be changed to protect anonymity and all data will be treated in the strictest confidence.

If you have any questions about this research, please contact
Lucy Poxon on Tel: 07888 849246 or
Email: lucy.poxon@btinternet.com

APPENDIX III

Recruiting leaflet for participants

**Feelings of
'stuckness' in
the grieving
process:
a qualitative
exploration.**



I am a trainee Counselling Psychologist at the University of East London. I am conducting research into feelings of 'stuckness' in the grieving process.

Call for research participants - can you help?

- Would you be willing to share your experiences of 'stuckness' to help us understand it better?
- Are you able to spare an hour for a one-to-one interview?

There are no right or wrong answers, it's your experiences that are important in this study. Participation will be confidential and separate from your counselling with Cruse. Following analysis, a report will be available for you.

If you are interested in participating in this research, please contact
Lucy Poxon on Tel: 07888 849246 or
Email: lucy.poxon@btinternet.com

APPENDIX IV

Interview Schedule

Interview Date: <input type="text"/>	Time: <input type="text"/>	Client Initials: <input type="text"/>	Pseudonym: <input type="text"/>	Tape Recording No: <input type="text"/>
Age: <input type="text"/>	Sex: <input type="radio"/> M <input type="radio"/> F	Time since bereavement: <input type="text"/>		

<p>1. When you are ready, could you tell me about who you have lost, and how and when they died?</p> <p>2. a) What were the main feelings that you were experiencing at that time?</p> <p>b) And what feelings are you left with now?</p> <p>3. You've mentioned that you feel 'stuck' in your grieving... we all have different definitions of feeling stuck...</p> <p>a) Can you describe to me how it feels for you?</p> <p>b) When did you become aware that you were feeling 'stuck'?</p> <p>c) How did you become aware that you were feeling stuck?</p> <p>4. What are the differences in how you are and what life is like since the death?</p> <p>Friends/family Going out/socializing Work/housework Sleeping/eating</p>	<p>5. How does your experience over the last compare with your previous expectations about grief?</p> <p>6. How does the way you've experienced your grief compare with how other family members have experienced it?</p> <p>7. How have family members and friends responded to your feelings of 'stuckness'?</p> <p>8. a) What led you to contacting Cruse?</p> <p>8. b) And why now?</p> <p>8. c) How do you hope Cruse will be able to help you?</p>
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APPENDIX V

Information Sheet for Participants

What is the study and why is it important?

If we can understand more about how people feel when they report feeling 'stuck' in their grief process and what it means to them, we can inform grief theory and the way we support individuals who have been bereaved.

What does taking part involve and what will happen to the information?

If you agree to take part in this research, you will be asked to sign a consent form and participate in a face-to-face interview with a researcher lasting for one hour. The interview will be audiotape recorded and transcribed verbatim for analysis. Only grouped information will appear and to ensure your identity remains confidential, a pseudonym will be used for your transcript and your personal details will be filtered out.

What sort of questions will I be asked?

The interview will be focused around how you experience feeling 'stuck' in your grieving process and how that sits with expectations that you and those around you hold.

If you have any questions about this research, or would like to take part, please call Lucy on 07888 849246 or email

lucy.poxon@btinternet.com

APPENDIX VI

Informed Consent Form

Consent to Participate in Research Study

Title: A Qualitative exploration into feelings of 'stuckness' in the grieving process.

I have read the information leaflet about the nature and purpose of the above research and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study will remain strictly confidential and the interview transcription will be anonymised. I understand that the transcription and digital recording from my interview will be destroyed once the research programme has been completed.

Having given this consent I understand that I have the right to withdraw from the programme at any time without disadvantage to myself and without being obliged to give any reason.

Participants Signature:

Researcher's Name:

Researcher's Signature:

Date:

APPENDIX VII

Debriefing leaflet

**Feelings of
'stuckness' in
the grieving
process:
a qualitative
exploration.**



**Thank you very much for taking
part in this research**

Feelings of shock, numbness, guilt, anger and anxiety are all very common reactions to what may be the most difficult experience of your life.

It is also common for people to feel 'stuck' or overwhelmed by these feelings and by sharing your experiences today in this research, you will be helping us to understand this further.

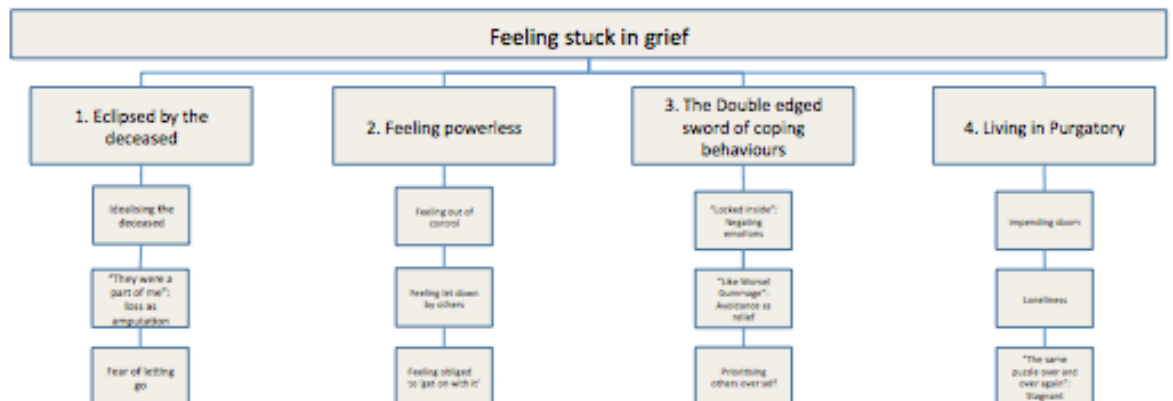
Following analysis, a report will be available for you to read.

You can contact me on Tel: 07888 849246 or
Email: lucy.poxon@btinternet.com

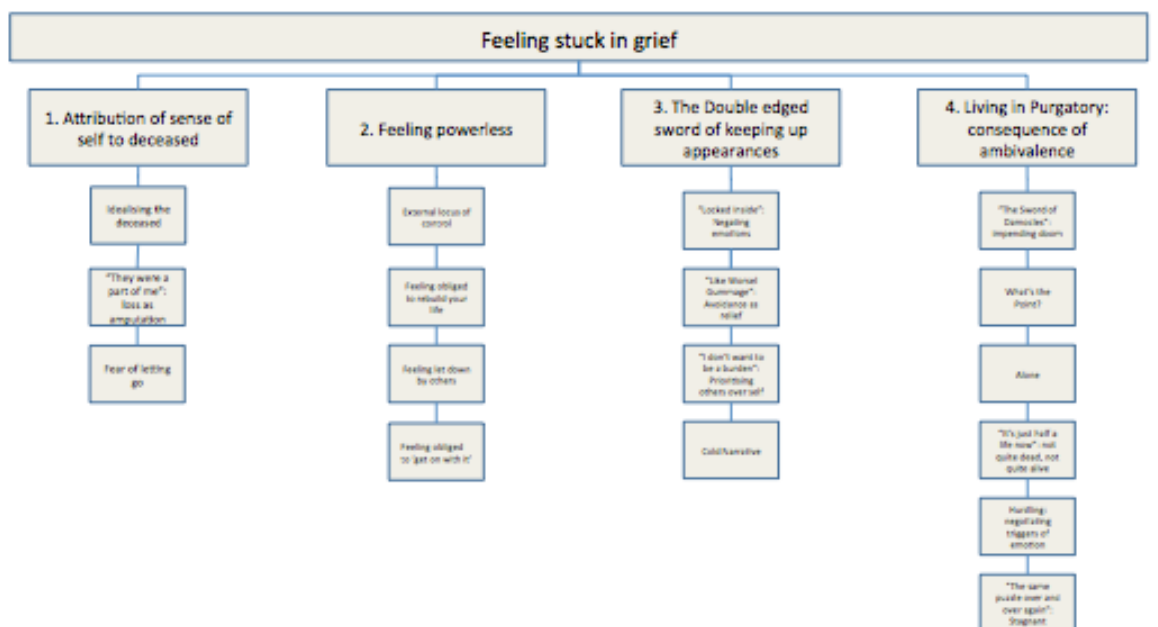
APPENDIX VIII

Pictorial representations of Themes – paper trail of analysis process

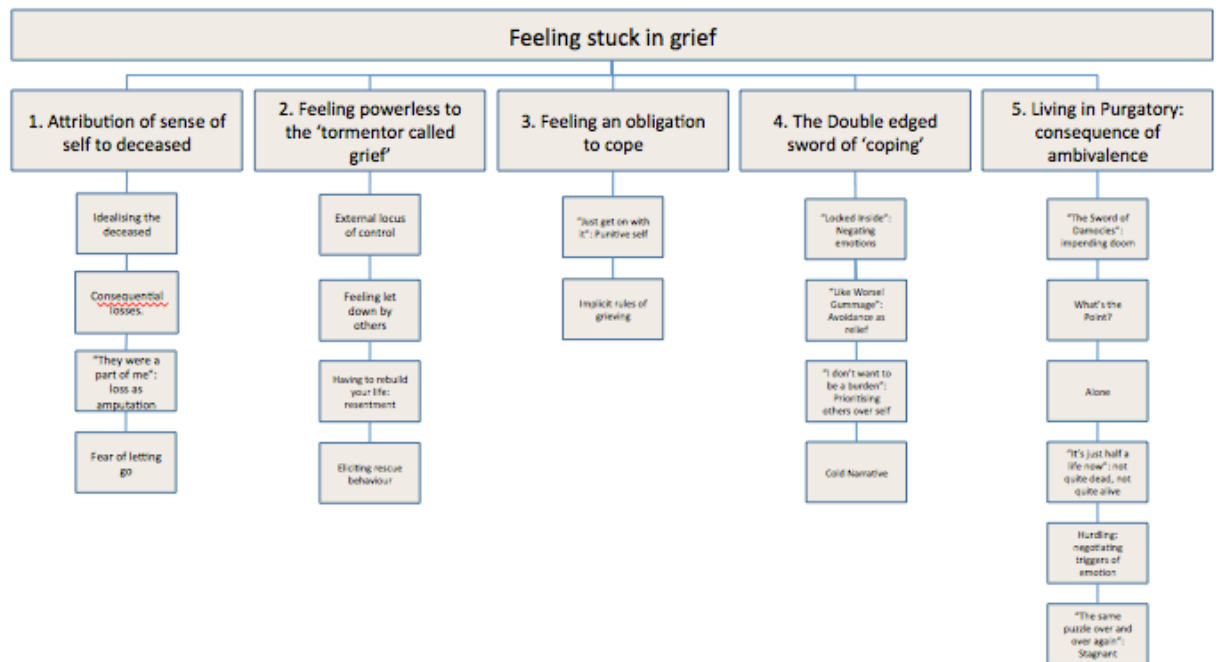
Final Version 5 – 22.3.13



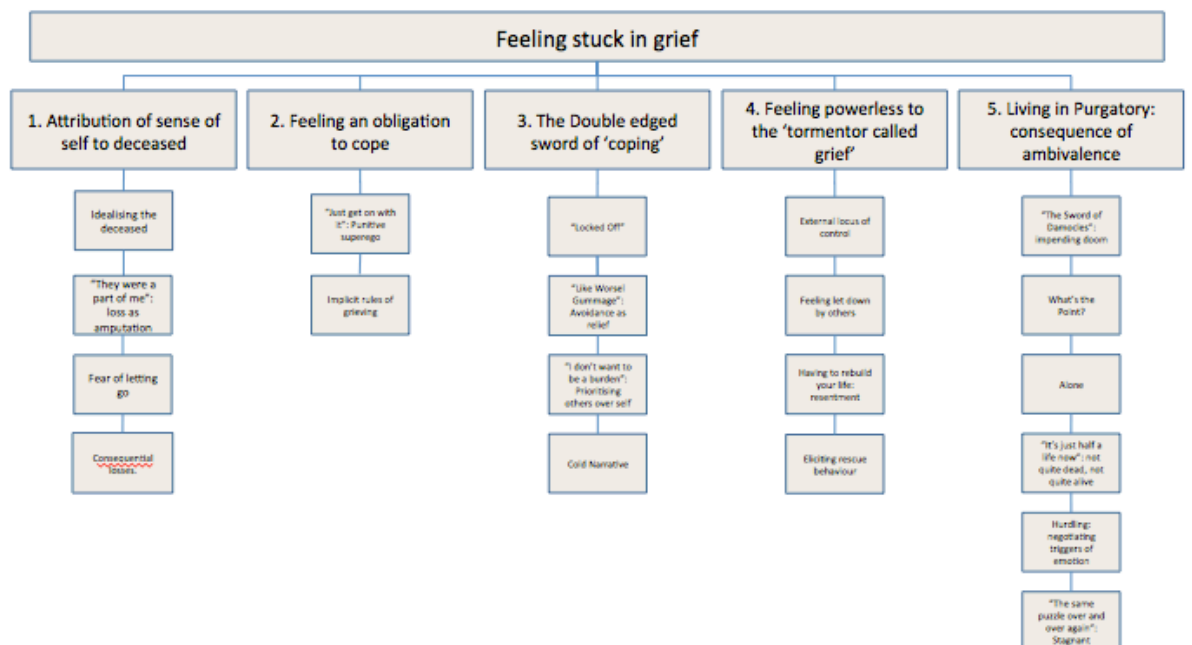
Version 4 – 28.2.13



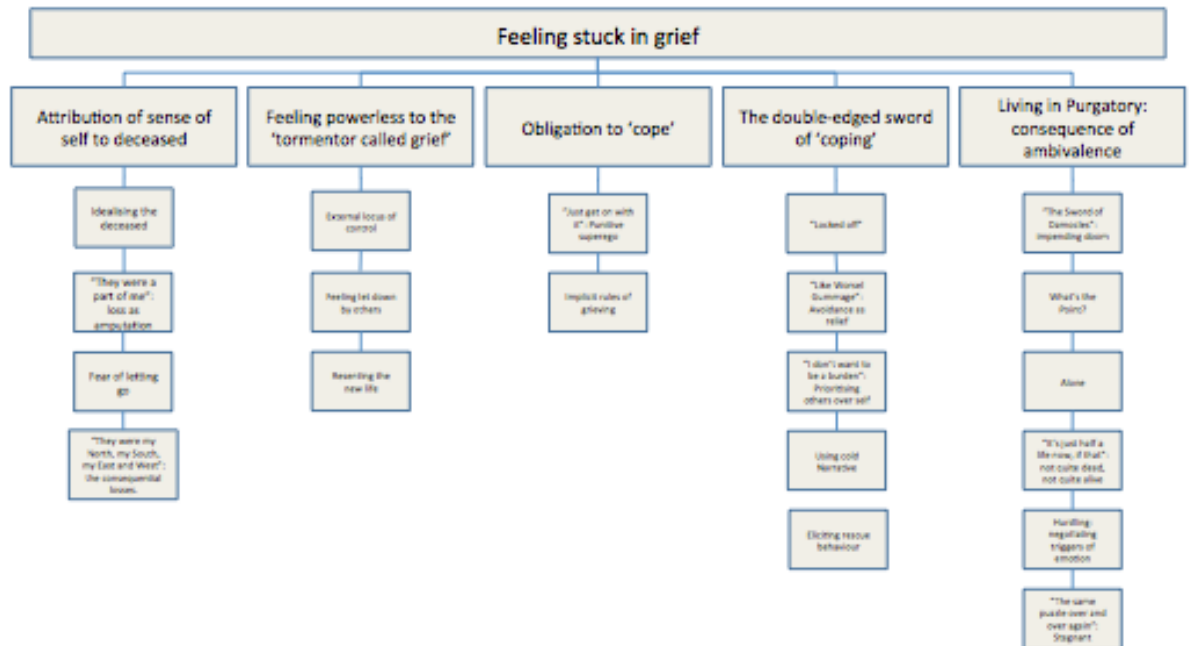
Version 3 – 16.2.13



Version 2 – 19.1.13



Version 1 – 11.1.13



APPENDIX IX

Illustrative quotes for themes – Master Theme 1

Master Theme	Sub Theme	Evidence from transcripts	Participant
Eclipsed by the deceased	Idealising the deceased	I haven't got a life now. My whole world ended when my Mum died, she was my best friend. She wasn't just my Mum, she was my best friend. We had huge... just such good fun and she was so funny. We had so much fun together, (293-295)	Mabel
		But she didn't just die. She didn't just die, I was prepared for her to die. Of course she was going to die, but not that day, not like that. No.	Mabel
		And he was very much a hands on Dad, erm and he was very keen to provide for everybody and do the right things. (10-11)	Jenny
		I suppose to some extent he was a little bit of a father figure. I mean he wasn't a father figure but because he's older than me, there was that sort of... [husband] did certain things and I...I sponse I took his lead on things.	Jenny
		I mean I don't have a Mum and Dad now but their deaths weren't anything like losing my husband. I mean obviously I grieved, but it was different. And it's how I feel about... my children because I feel that... yes they grieve for him, of course they do. But they've got their own lives, they've got their own lives to lead. He was a part of their lives but only a part, they've all got their spouses, three of them have got children. They've all got their own things that they're up to erm and I'm not saying they don't grieve, and I'm not saying they don't find it hard, but for me he was sort of like the centre of my universe if you like. (428-436)	Lorraine
		A unique position, much as I love my children to bits and would do anything for them, it's still a different relationship. (438-439)	Lorraine
		I felt that he was the one, end of, one do you know what I mean, we used to see each other every day. Um, I just thought he was the One (14-15)	Sandra
		just remembering the days that we had, the good days and the bad days... so we didn't have many bad days and just think I wish that he was still here. (48-49)	Sandra
		You know its bad to say that, it's your mother but it didn't hurt as much as my partner did, because I feel like I loved him and we had our future in my head, do you know what I mean, our future ahead of us. (121-124)	Sandra
		And I feel she was... stolen from me. (147)	Mabel
	"They were part of me", loss as amputation	you become a partnership, you know whether it's a good or bad partnership you know you operate together. [] And so you lose a sense of who you are. (263-287)	Jenny
		you know I felt although I did have a bit of time off, but I had lots of things to sort out. I'd felt that, you know it was important for me to carry on working. (301-303)	Jenny
		And I've...I've suddenly, I've sort of suddenly realised that I find that really difficult because yet again, it's sort of... ok, we've got to do the birthday and it's the incomplete family. (469-470)	Jenny
		it's only recently that I've sort of quite taken on board... maybe it's because my Dad died, that it's different if you're a child or a partner or a parent and you suffer a bereavement. (500-502)	Jenny
		Half of me is missing. That's how I feel (182)	Lorraine
		You know sort of, we went together [] And I just feel that I've lost my arm or something, I just don't feel complete. (185-187)	Lorraine
		They were a part of me, like an arm, a leg do you know what I mean, I have...a part of the puzzle in my heart that's made me.	Sandra
		And now I just feel...like I'm hanging on the edge of this big dark hole and my fingers...are just my last fragments of sanity and that relentless tormentor called grief is trying to peel my fingers away from the edge of that hole. And I don't where I'll go when my fingers come off. (cries) (191-194)	Mabel
		And I think maybe that's something to do with being stuck, because there is a time when you have to let some things go. (248-249)	Jenny
		Erm, so I can generally, I tend...things tend to build up and then I can't cope. (346-347)	Jenny
	Fear of letting go	Erm, and I think, I mean I think you do have to feel it quite deeply before you move on. (698-699)	Jenny
		it was awful. I just sobbed and sobbed sat on a bench in the cold, damp erm. And er, I had...I had, I took a week out really I didn't do anything. (32-13) I look after my grandchildren two days a week and I didn't look after them, I volunteer at the hospice one day a week, I didn't do that. And I just...I was just exhausted. And er, that I would say was really my very lowest spot (261-263)	Lorraine
		makes it seem further away. And it makes him seem further away. [] And less accessible and just more remote, and I don't want to lose him and I don't want to forget him (330-333)	Lorraine
		I felt in some ways if I... let go to grieve, A) it was self indulgent and B) I might not be able to pick up the pieces again. (380-381)	Lorraine
		And she said it's the only person that really knew her brother as well as I did and so its nice for her... "do you remember when we did this" and... So its quite nice, but I still can't... feel I can let go (57-59)	Sandra
		But... do you know what I mean, just go past to and fro, just remembering. So I feel like I'm quite stuck in that respect because I can't let go. (64-65)	Sandra
		I don't feel like I dealt with my nephew that much, do you know what I mean, I was just too wrapped in my partner. (92-93)	Sandra
		I believe being stuck means stuck on...my only definition is stuck on the past [] You just can't let go. (348-351)	Sandra
		I find next to the grieving process is acceptance, know what I mean...accepting that they've gone. Yeah and I have. I have accepted, know what I mean...that I am on my own now and do you know what I mean, I've accepted that they have gone and they've got their reasons and that, but... I still have to remember them, I still have to open that book, but I don't know why, I feel I have to (429-434)	Sandra
		I think it's because they were very close to me, that I find I just can't let go. They were a part of me, like an arm, a leg do you know what I mean, I have...a part of the puzzle in my heart that's made me. (443-446)	Sandra
		And I think that's why I can't... that's why I'm stuck, why I can't let them go because if I let them feel I let go, I let myself go. Know what I mean, a part of me go.	Sandra
		So to me I think it would class me as, in my mind as heartless. [] Erm, because that's my love for them do you know what I mean? [] In there (points to heart). And if I don't let... you know if I let them go, I will feel that you know that's part of my love and part of me, that would go as well. (462-469)	Sandra
		I'm very insecure and trust is a really big issue. And poor [son], my son. Bless him, he just... I just wrap him in so much cotton wool even though he's 14, do you know what I mean, he has to be in by 9pm and silly things like that. He has to tell me where he is going or I start getting the hump. He say's "Mum, I'm 14, you know, I'm soon going to be old enough to do what I can". I say "I know but you're the only one"... (514-519)	Sandra
		otherwise because like for example, you know, if I had a test or something tomorrow, I wouldn't be able to sleep, I'd be worrying and then a worry would start me getting open that jigsaw puzzle...when was the last time I was worried? Oh yeah, when the boys went, and it goes to my boys, to my sister...rah rah rah rah (makes spiral shape in air). And like "Stop", do you know what I mean? Deal with it tomorrow (laughs) you won't have time to worry about it then because it will just spiral back down to my childhood. To I remember at 2 years old. So I could just go... rah rah... it's a slide. (637-646)	Sandra
		I think, I think again, as I said with [partner], as he died in his sleep and was very young and he was the love of my life, it was a different love to when you get your family, family love. It's a different love. [] And I think, he was the one that has hurt, that I found really hard to let go out of all of them, he's been the number one.	Sandra
		Exactly, that's what hurts more. If I knew that they'd be looked after, and he'd be a proper Dad to them, I would be able to let go, fine. (796-797)	Sandra
		I just... you know, I can just tell by their body language, read people, you're not really interested so I'm not going to go any further. (874-875)	Sandra

Master Theme 2

Feeling out of control	This woman who was very pleasant, very nice lady, she sat there and she told me exactly what I knew. She said 'I am seeing a woman that is absolutely distraught with grief'. I know that, that's not why I'm here, you know this is just ridiculous. My God, I think I went there four or five times, this is pointless, absolutely pointless. I don't know what I'm looking for, I don't... I know there isn't a magic pill that's going to make me feel better but surely something must. (265-271)	Mabel
	So there we are, I haven't got the money to sue the NHS and that's what eats me up, it kills me everyday. (96-97)	Mabel
	So as far as I'm concerned, my mother was killed that day and there's absolutely nothing I can do about it. (188-189)	Mabel
	I don't know how I did it. I don't know how I did it (sighs). But there wasn't anybody, and there aren't any organisations that help you. (262)	Mabel
	I was cheated, I was cheated [] And robbed, (cries) of extra time... with my Mum. I was robbed of it (cries). And they've all lied about it, and I'm not making it up and I don't believe for a moment that I'm kind of imagining things because what I've said to you are the facts. And you as a detached person surely can see my point, that it doesn't seem right, what happened.	Mabel
	I had a very very good friend that, it turned out that she, this sounds petty when I say it really... but anyway she was using me because she wanted to have a horse, she wanted to absorb all my knowledge, she wanted me to help her find the horse for her to buy, which I did do. Then when she got all of that, she then didn't need me anymore, so there we are. (662-666)	Mabel
	2 years ago tomorrow and she was killed (cries) <u>as far as I'm concerned</u> , she was killed. (3) And I feel she was... stolen from me, she'd been... she was murdered <u>as far as I'm concerned</u> (147) So <u>as far as I'm concerned</u> , my mother was killed that day and there's absolutely nothing I can do about it. (188) <u>It's just like</u> someone was murdered and they've got away with it (331)	Mabel
	'So now I'm stuck in this terrible place (cries) and I can't get out of it because... there's so many things that I wanted answered that weren't. (144-146)	Mabel
	But they all know very well what happened... (sighs). Yeh, they know very well and you've always heard that expression of closing ranks, mustn't that look like it to me... Yes. (176-177)	Mabel
	And now I just feel... like I'm hanging on the edge of this big dark hole and my fingers... are just my last fragments of sanity and that relentless tormentor called grief is trying to peel my fingers away from the edge of that hole. And I don't where I'll go when my fingers come off. (cries) (192-195) [] Just go along, grief and pain keep poking you and prodding at you all the time, trying to lift my fingers off the edge (cries). I don't know what to do...	Mabel
	I have this massive regret that I didn't give up work sooner. That I hadn't had that summer of quality time with her. Why did I wait til it was too late to give up work? I don't know. (sighs) I don't know why I waited so long, I suppose I didn't believe she was so ill. (301-305)	Mabel
	I'd like to do more, but I don't know if I can. (411) (painting)	Mabel
	I have an open mind because I just seem to have been shunted from one person to the next	Mabel
	Cos you know the ambulance people come and then they call the undertakers and its all taken out of your hands... or the attempt was that... There were certain people who thought 'how dreadful, let's get the body out of the house' as soon as possible which isn't how I would necessarily have chosen and I think the problem is you don't... unless you've actually encountered it... you know this is my first encounter really... of somebody dying and being responsible is that erm, you're not really given the choices. (48-54)	Jenny
	cos its sort of presented slightly that you don't have a choice. And I think... I think its well intentioned, I think its... they want to try and save you. (90-92)	Jenny
	But I mean in some ways you do accept reality a bit more because, you know, you have to. You don't have a choice do you? [] You know, you can't have that... I mean arguably you can have that conversation, but you can't concretely... you know... that's gone. [] In... it's changed, it's changed totally. And there's nothing you can do about that. (450-457)	Jenny
	Because after a while, and this is probably a stuckness... [] I think its very easy... to... give yourself, or give the excuse... that your husband died. [] And although it might be partially true, its not entirely true, because its not what happens to you, its how you deal with what happens to you (laughs) [] So I think that is a sort of stuckness, is that you can... not exactly well sort of over and done, or get into a habit of... that's your reaction to something.	Jenny
	And then you start well thinking people are only being nice to me because I've had some nice time, erm, nasty time I mean not because they really like you. (733-735)	Jenny
	I mean I do, I do believe... that... life will look after you if you let it. [] Its bit dodgy grounds though, I mean I am a, I think deep down I'm a quite... I'm a bit optimistic, (864-868)	Lorraine
	this just sort of feeling inside that I didn't know what I was doing and I felt... sort of like... sort of climbing the walls but... on edge, didn't know where to put myself, didn't know what to do. And I thought I've just got to do something (491-494)	Lorraine
	Once January came, I'm having to say my husband died last year. And... it's like time is moving me on and I'm leaving him further and further behind. Whether I wanna move on or I don't, I haven't got a choice, time is moving me on (322-325)	Lorraine
	Society is closed isn't it, closed the door, everyone's too busy for everyone now. There's no one there to help anyone now. (883-884)	Sandra

Master Theme 2 cont'd

Feeling let down by others	And I tried hard with her, Pilgrims Hospice, Social services and everyone to get some help, but I couldn't get any. Nobody helped. (10-11)	Mabel
	the physiotherapist turned up, she was late because it was snowing. She came in and she was a Pakistani lady, she didn't look at Mum's notes. (30-31)	Mabel
	I said 'is she breathing?' and she said (shouts) 'no, I don't know' and she started completely panicking. (48-49)	Mabel
	the ambulance couldn't find us, they went up there miles up the road away from us. (69)	Mabel
I had a solicitor and he was useless, I can't believe it. (87)	Mabel
	Because this woman, this physiotherapist, she denied making my mother stand up, cos she knew she shouldn't have done. She denied it, when she said my mother wasn't sick. (87-89)	Mabel
	she's actually saying to you, you've got a case, you could sue the NHS for negligence. You know, it was. If they thought my mother was dying, why the hell did they send a physiotherapist (sighs). (94-96)	Mabel
	And the...the pathologist was so Greek you could not understand a word he said. (113-114)	Mabel
	And I said to the policeman at the time, 'she made Mum stand up'. I've told everyone, the ambulance people, all of those people. [the coroner] refused to call them as witnesses. (136-138)	Mabel
	My own GP that also treated my mother. I went to him and I said to him 'I want to complain about this physiotherapist' and he said 'why don't you just move on?' he said 'why do you want to ruin someone's career?'.... How can I ruin someone's career if she wasn't responsible? And then...he wrote to me and said 'I refuse to see you anymore, I feel our relationship has broken down'. (154-158)	Mabel
	Yes...oh how amazing (cries) doesn't all of that make you think, 'hey what's going on here?' (160-161)	
	They sent someone out from the mental health crisis team about a week after mum... two weeks... something like that, after she died. I didn't like her very much (laughs) and she said to me... she gave me leaflets. Brilliant. Everyone needs a leaflet, don't they? (227-230) So I didn't want to see her anymore. She just sat there and basically talked about her French holidays. Brilliant. (238-240)	Mabel
	I went for counseling at the Pilgrims Hospice...pointless. (264) She said 'I am seeing a woman that is absolutely distraught with grief'. I know that, that's not why I'm here, you know this is just ridiculous. My God, I think I went there four or five times, this is pointless, absolutely pointless. (266-268)	Mabel
	And I wanted to know, exactly when she would be at the undertakers, where she wanted to be, where I knew she wanted to be where my Dad went. So I phoned the undertakers on several occasions, and 'no, she hasn't arrived yet'. And I said please, let me know. But they didn't. It was nearly two weeks and I phoned up and said 'is my mother...'. 'Yes, she's been with us for three days'. (735-739) I said 'You didn't tell me, you promised you'd tell me'. I went beserk. (741)	Mabel
	And it said in the leaflets that erm 'approximately six weeks after death you will start to feel better'. Six weeks? Where did that come from? (230-232) And then it said 'typical...typical things you can expect is when you're out you see someone that looks like the bereaved, and when you're this you expect to see them there.. and that...and then another six weeks on you should be feeling this and another six weeks after this you should be feeling that'. Oh that's really helpful, yeh really really good. So I didn't want to see her anymore. (234-239)	Mabel
	Six weeks, you're meant to feel better in six weeks. And I was hopeful that I would, because this leaflet... [] said I should. (245-248)	Mabel
	Everyone comes round don't they the day after, they always do. You never see them again (469)	Mabel
	I just didn't feel any better and as the time goes on the pain gets worse and they say time heals. It doesn't (578)	Mabel
	People avoid you when you start crying, they can't cope with it. (588)	Mabel
	And I did try and do everything everyone said you should do, I did. Yeh, I went out with the dogs, I did this and... (250-252)	Mabel
	I don't know what I'm looking for, I don't... I know there isn't a magic pill that's going to make me feel better, but surely something must. (270-271)	Mabel
	I have an open mind because I just seem to have been shunted from one person to the next (646-647)	Mabel
	A number of times you meet somebody, and they say 'Oh we must have coffee' and you know 'I feel so bad I haven't been in touch'. And you know it's not going to happen. (660-662)	Jenny
	Actually this was at a time when, I had been on anti-depressants and I'd come off them because he'd given me some new ones and they didn't agree. [] And he s... he had said they should be just the same so I assumed that he was right [] So eventually when I went back I said, look actually I couldn't get on with those at all, he said 'No, half the people couldn't'. [] Ah Thanks (746-756)	Jenny
	and I just said to her you know, I sort of I asked her whether she's had bereavement training, and she said 'No'. So I said did she think it would be a good idea to go to somebody. She said 'yes why not' (laughs) (780-783)	Jenny
	I've sometimes found it quite upsetting because I feel that I express myself much better than I used to, and she'll suddenly say 'well you're not expressing it, you're not saying anything, you're not expressing, I've no idea how you feel.' And I think, I just told you. (801-804)	Jenny
	I rang the Samaritans cos I was climbing the walls. Erm, but in all honesty I didn't find that much help. But bless their hearts, that wasn't their fault. (496-498)	Lorraine
	ah bless his heart I got a young chap, well he sounded young and he obviously...well he said he had no idea...no experience, personal experience of bereavement. So, with the best will in the world, he couldn't empathise (512-515)	Lorraine
	I've got a lot of blame on the doctors this time, doctors saying... the fact is because they said he had a cold, nothing to worry about then suddenly it's meningitis, they couldn't revive him and he passed away. I was more angry at the doctors sort of more than anything. (80-83)	Sandra
	But you know, very selfish that you go, what about me, what about my sister, do you know what I mean? Me and my sister, erm. (113-114)	Sandra
	But erm, the NHS ones weren't very good [] I just felt like I was counseling them. You know, one of those, you feel like you're telling them because they want to hear? I mean they weren't very good. (609-613)	Sandra
	Mum turned to drink, become an alcoholic. Tom, Dick and Harry came to the house and I got sexual abuse from one of the men that came into the house. Never told my Mum til I was about 14 years old so I kept that inside since I was 5. Do you know what I mean?	Sandra
	So... he was like I'll come round on Saturday to see you , and I said as long as you don't get into trouble but I was so worried about him getting caught, I phoned up his school and said about the situation. And apparently they called Dad in, said that I phoned...which cos I didn't know what to do, do you know, Oh my God, I don't want them getting caught (cries) (802-807)	Sandra
	I remember going across the road, do you know what I mean to talk to the lady across the road, dur dur dur dur... But no one's got that now, everyone's too busy, everyone you know what I mean? (879-881)	Sandra
	You know, with past relationships you know, my best friends taking my partners, or you know stealing something from me, do you know what I mean? Belongings and things, and I think 'you're not helping my trust issues here! You're not helping me'	Sandra

Master Theme 2 cont'd

Feeling obliged to 'get on with it'	I just didn't feel any better and as the time goes on the pain gets worse and they say time heals. It doesn't (579-580)	Mabel
	No... people avoid you when you start crying, they can't cope with it. I found that, all the people like I said, you know that turned up after Mum died 'Oh anything you want J, just let us know'. You phone up and suddenly they're busy. I never phone again. (588-591)	Mabel
	she gave me leaflets. Brilliant. Everyone needs a leaflet, don't they? And it said in the leaflets that erm 'approximately six weeks after death you will start to feel better'. Six weeks? Where did that come from? (229-232) and then another six weeks on you should be feeling this and another six weeks after this you should be feeling that'. Oh that's really helpful, yeh really really good. (236-238)	Mabel
	Six weeks, you're meant to feel better in six weeks. And I was hopeful that I would, because this leaflet.. [] said I should. (244-247)	Mabel
	When she died I had erm three people from the village. [1]Everyone comes round don't they the day after, they always do. You never see them again (469-471)	Mabel
	And I thought that it was quite important that they saw him before... I mean obviously he'd been tidied up but... saw him before he went so it was... real. (77-78)	Jenny
	erm the children went back to school the first day, the day after. It was their last day of term before Christmas and...I think they wanted to go and I felt that it was good that they wanted to go.	Jenny
	I felt quite keenly after the two year mark, because you know in education and things, they sort of make allowances for two years I think. [] You know you can sort of say, well look this child might be affected by that. I think that's the sort of...that's my understanding of it. Lucy: Ok, so you were heading out of two years thinking, I will feel better but I'm not? Jenny: Yeah, so there must be something wrong with me, type of thing. (528-535)	Jenny
	Because I know all the sayings about you shouldn't make big decisions so quickly but the term of rent was coming to an end	Lorraine
	Cos, you... you can't talk to family, bless their hearts. They're going through it as well (259-260)	Lorraine
	I don't think... until it's your own grief that you can possibly have the first idea of what it's like. (413-414)	Lorraine
	That it was left behind, and then seeing all these people, and then seeing that woman that stopped me from seeing my father, do you know what I mean, I was quite angry. And as I say I got into depression for... for about a year, do you know what I mean, I was really bad... bad way. (166-171)	Sandra
	Yeah, you have to get over that anger period I suppose, anger and then the grief, and accepting that they have gone. (982-983)	Sandra
	"Six weeks, you're meant to feel better in six weeks. And I was hopeful that I would, because this leaflet.. [] said I should. [] But I didn't. And I did try and do everything everyone said you should do" (244-249)	Mabel
	yet I suppose something that happened, has happened to me after the two year thing is that I find it harder... to talk to the children in a way about... because they have this sort of... 'ok, get over it'. I don't mean it quite like that but...[] That's in the past, cos of course it's further away for them in terms of their lives isn't it? (474-476)	Jenny
	Because you've got to grin and bear it in a way. I mean you've just got to get on with it. [] And you know that you've got through the first year, you know that the sort of emergency's off in a way (545-549)	Jenny
	So I think it's important for my children that I sort through my stuff because otherwise your sort of pass something on. (619-620)	Jenny
	So I think it's a little, people feel able to tell their stories, which they may not have done previously. And... erm.. in a funny way especially if you haven't heard about it, it makes you realise that life has to go on. (642-644)	Jenny
	I know somebody saw me and she said something like 'well of course you're sort of the first of our generation' so of course everybody's watching to see how you're coping. She, it wasn't unkindly said, it was... but I think you do feel a bit watched.	Jenny
	The number of times that, you know if I'm down... people say 'Have you been to the doctors for antidepressants?' Get a lot about... [] because the expectation is that you know, you get over it, or that...and you've got to cope. Maybe they're worried that... going down under, I don't know. (691-698)	Jenny
	The solution is, you know, shut up. (704)	Jenny
	I mean I do have a pattern of doing too much and then not coping. (775)	Jenny
	and those times, I've just been soldiering on rather than... managing myself (816)	Jenny
	You know because there is...there are things that you don't particularly want to confront or want to do. [] But they still need doing. And I suppose... because people say take one day at a time, and there are times when you do what you can and, but actually there's still things that need to be done even if you put them on the back burner. At some point you've still got to do them. (837-843)	Lorraine
	well... I mean you have to get on with it. Erm you have to get on with life, there's all this stuff to do. (124-125)	Lorraine
	Because you know, the Bible says there's no marriage in Heaven so I know I will see him again but... not as we were so what has gone has gone (cries). And I think it's the finality of it that's so... painful...	Lorraine
	You know, that's it. Hard cheese, whether you like or you don't, and obviously you don't, you just have to get on with it. [] There's no other way, you either get on with it, or you go under and I'm not the sort of person who would go under. (211-215)	Lorraine
	You know, ok I've lost my husband, even horrible as it is there are plenty of people far worse off than I am. Erm, I'm blessed in so many ways, erm and I think you've just got to get on with it (376-378)	Lorraine
	to start with if I cried I sort of thought 'for goodness sake [name], pull yourself together, get on with it, you've got to get on with it' You know, ok so he's died, so tough that's the way it is. You've got to get on with it. (385-387)	Lorraine
	I was just, I'd got to a point where...I think I was just nearly tearing my hair out. I didn't know what to do, I didn't know... I knew that I couldn't stay as I was. Whatever state that was, I knew that I'd got to do something, I'd gotta move on, I gotta do something... Positive. (477-482)	Lorraine
	And I just got to August and I just thought well I've gotta start really coming up with some ideas, coming up with a plan for moving forward (486-488)	Sandra
	You know its bad to say that, it's your mother, but it didn't hurt as much as my partner did, because I feel like I loved him and we had our future in my head, do you know what I mean, our future ahead of us. []And then there's my Mum, that didn't want to be here, so...(121-126)	Sandra
	I just think other people have so many other problems, they don't want to listen to mine, or I feel that way. You know, there's people far worse than me out there, so why...know what I mean...why should they be listening to me. That's how I... come across to people.(292-295)	Sandra
	But I refuse blank to have medication, so as soon as I've...blah blah blah... and in my head it sort of comes a bit clearer. And then I can go back home. "Right, that's enough, sort it out!" (617-619)	Sandra
	I find, you know, a lot of people do that and it's not very good for them, they should look, you know, for today. Forget about tomorrow and yesterday. Live for today, and that's what people should do because that's what a lot of people do get into depression, due to being stuck thinking about the past, what happened in the past. Do you know what I mean, been abused or... You know lost families, you know or... do you know what I mean, there's lots of things: bad childhood, (inaudible speech) ... good childhood...people just get stuck. They should just forget about it, do you know what I mean. I know it's hard to say just forget about it, but sort of deal with...open the book, do you know what I mean and do the puzzle, then close it, then put it away. (351-362)	Sandra

Master Theme 3

The Double Edged Sword of Coping Behaviours	Negating Emotions: Locked Inside	Yeh, I'd like to do that as a living really, so I can stay here and not have to go anywhere. I find it very hard going shopping. (419-420)	Mabel
		I didn't really have any. I sort of declined with friends when I started looking after mum. I've never been a people person, I've always been an animal person. (658-660)	Mabel
		But I've got a bit more introverted now. Its partly a confidence thing, I think. You know self esteem, self confidence. You have to...you have to sort of build it up from yourself don't you rather than...enjoying someone else saying nice to you. (518-521)	Jenny
		So I suppose yeah, I had thought about it a bit, and the widow of our friend. After a couple of years, didn't want to know about anybody. (583-584)	Jenny
		And I think her answer to it in a lot of ways was burying it [] And trying to control everybody. (611-613)	Jenny
		I mean there's everything else...I didn't cry but I found it hard [] I'm sort of conscious of them. I was busy, wasn't the time to sit and have a cry. (171-177)	Lorraine
		So I didn't have any time on my own, I didn't have time to sit and reflect, remember. Didn't have a chance for any of that and cos by the time the funeral...er the wedding was over and we'd got back and everything was sorted out, erm in a way the moment has passed. (229-232)	Lorraine
		Erm, so and I know that I'd got stuck over [sister] so when it came to [husband] dying, I had in my mind that I didn't want to get stuck because I know also that you have to grieve because if you leave it locked inside you'll pay for it in some way, it'll come back and bite you somewhere. (237-240)	Lorraine
		But, certainly after I lost her and that, I got depression and I, erm went for Cruse counselling, didn't need to go for very long but it was like it needed unlocking. (246-248)	Lorraine
		I realize a lot of I was numb. Erm, but I wasn't grieving, not in that...I'd have a cry...that sort of thing but not what I would describe as, subsequently describe as grieving. (251-253)	Lorraine
		At the start of this year, I found it very hard because... when I say hard is when I sit and cry. (318-319) <i>expressing emotions represents a negative experience where control over being locked off has failed.</i>	Lorraine
		But it's just, you know its just so painful, so awful and I think you have a... time of grief and then you can't take any more and you have to stay, sort of put up the shutters and say 'I can't cope with anymore'. (366-369)	Lorraine
		No, no, I don't tell them, erm because I don't want to worry them, I don't want to upset them. Erm, I think they're working through their own stuff (443-444)	Lorraine
		I certainly won't be sitting around being mournful. Because, if I'm mournful it'll be when I go up the crem in the morning (460-462)	Lorraine
		I got through it but only by stealing myself, have to sort of, you have to sort of switch yourself off from compartmentalize yourself. And that was how I got through it. (571-573)	Lorraine
		Cos I'm the sort of person that don't really talk about how I feel. You know I'm one of those friends, "you just tell me yours" you know "mines are boring, you don't want to hear mine" I'm one of those sorts of people, do you know what I mean.. "you tell me all yours, you don't want to listen to all mine". (282-285)	Sandra
		I don't talk...never talk about how I feel and he hates it because I always moan "You never ask me how I feel" and all that and he's like "well you never tell me"(288-290)	Sandra
		Nan's very hard, very hard woman. Do you know what I mean, sometimes I want to talk to her about my Mum, because my Mum's... parents about erm...and my Mum and she doesn't like talking about it, she's just like you know... locked off. (327-330)	Sandra
		As I say, lots of lots of insecurities []...I have about... and trust in people. []Hm, and I find it very hard...well people find it very hard to get close to me due to it. Because I feel, you know, you don't want to get close to me and even though I try and get close to them, I don't know it's just I feel like... that's the sort of person I am. (503-510)	Sandra
		You know I'm lucky, I have some good friends. But again, do you know what I mean, I'm at arms distance when it comes to myself, but I'm there, you know, click of a finger for them. [] Because I guess, of the sort of person I am, it's the fact is you can tell me all you like. Mines' depression, do you know what I mean? Depression, you don't want to listen to mine. (492-498)	Sandra
		the doctors think it's my psoriasis, I've got psoriasis. [] This is my... you know it's got... I'm having treatment at the moment and it's looking good at the moment. But erm, that's due to stress and anxiety they say, but my doctor thinks that's my shell. He says that, do you know what I mean, it seems that you know, you're quite happy for it to get quite bad []Because then you know that no one's looking at you, no one... do you know what I mean... approach you, it's your... your shell. (535-543) he just says I think it's just part of your shell, do you know what I mean, if you make it worse, then... then we know you're getting quite depressed and low because you just let it go. (549-551)	Sandra
		Mum turned to drink, become an alcoholic. Tom, Dick and Harry came to the house and I got sexual abuse from one of the men that came into the house. Never told my Mum til I was about 14 years old so I kept that inside since I was 5. Do you know what I mean? (656-659)	Sandra
		And that's what worries him, because I'm so strong minded, that's what worries him even more, thinking well what are you thinking? (839-840)	Sandra
		Thing is if they've got something on me, they'll have something on me... especially my partner. Something like, if I start, you know, feeling...say something, you've got something on me emotionally. [] Something to use. It's due to my background, you know, my childhood. (844-848)	Sandra
		So yeah. So I find myself... I don't let anyone in because again, I do let one in, because as soon as you've done something wrong, that's it you don't get no more chances. One time, he came in drunk, my partner, and erm kicked my door and made a massive dent in my door. And since then, that's it our relationship's over, I don't want you near me. I don't love, you do you know what I mean? My barriers are up, that's it. (904-909)	Sandra
		It's not "of course you can" and help each other out. There's none of that nowadays is there? [] Well I haven't seen it (laughs) for a long time. Everyone's out for themselves now, and I think that's made me even more... closed in. (886-890)	Sandra
	Like Worsel Gummage: Avoidance as relief	Yeah, which I wish I wasn't this strong sometimes and I wish I wasn't so hard on people, but it's just the way that people around me have made me. (1014-1015)	Sandra
		I just can't move forward, I never feel better, I never have a good day, I feel just as bad now as when she died. And the erm, do you mind if I have a cigarette? (221-223)	Mabel
		I go to bed exhausted because all day I try and keep so busy. I walk for hours with the dogs, and I've got a field I poo pick after the ponies. (sighs) (323-324)	Mabel
		It's just marvelous, absolutely marvelous. It doesn't matter what the weather is, I walk and its wonderful because my poor little mind actually has a rest. [] It really does, and its amazing how I... you think when you walk you might think, but I don't. I don't think. I just... (383-388)	Mabel
		And I don't think when I draw, either... [] Yep, I don't...my mind is just on that.(400-403)	Mabel
		He was overworking, doing too much. He wasn't happy at home, he said that in his relationship but he wasn't brave enough to move on. He was working 7 days a week, do you know what I mean, 10 hours a day. He was working really hard because he didn't want to go home. (147-151)	Sandra
		In my head, if I could just... get a new one (laughs) [] Make life much easier... [] Yeah, like Worsel Gummage, you remember...change the heads. [] Do you know what I mean? Would be so much easier. (409-415)	Sandra
		I learnt how to...you know, because when you think of something, it leads to something. I've learnt to switch off now, and think right, work... once work's finished you'll go to sleep and then I'm quite good. I've trained myself, to say "Right, Goodnight" to shout at myself "Goodnight!" to yourself to make sure that I don't... [] because I wouldn't be able to sleep otherwise. (560-568)	Sandra
		I will find something to ex... my brain because my brain will go overdrive again, I'll just go low until I end in depression. I need something for distraction. Lucy: So you keep busy. Sandra: Yeah, I do. Like with my anxiety to leave the house, I get distraction, I put my Ipod on, or I'll take a book with me. Some sort of distraction...(578-583)	Sandra
		Lots of distraction. I've trained my brain... to distract. [] Which is quite good. [] Done it all on my own (laughs) Do you know what I mean, I've trained it to behave. (584-590)	Sandra
		sometimes it beats me, and I get very pissed off when it beats me.[] And this is when I get quite low and depressed... [] ...when it beats me. [] So I go back to the doctors, and say... I will not take anti-depressants. I refuse point blank, I just think..."No". I'll let the doctor just listen to me for 5 minutes or can you let me have a counselor for a little while or something for me to rant and rave. So it helps me clear my head, and then I'll be back again. (592-603)	Sandra
		And then, do you know what I mean, I do. I just snap out of it. Lucy: So from somewhere you get this incredible strength? Sandra: Yeah, exactly from somewhere. I don't know where it comes from but I'm not going to question it. Lucy: Right. Sandra: Because it's kept me going (621-626)	Sandra
	Prioritising others over self	Cos I find that ... well, [Cruse volunteer] says it's my strength and my weakness, sort of like a double edged sword, is the fact that she says I'm strong and erm I get on with things [] Erm, I'm blessed in so many ways, erm and I think you've just got to get on with it and I think that was...really where I was concerned that I would get stuck (Lorraine 374-379)	Lorraine
		And I was like, again, push my feelings away from how I felt about my sister going. I was concentrating on these children, these children need me... I haven't got time to grieve, I haven't got time to... you know, I've got to house them, I've got to get new schools...dur dur dur. I've got to sort a funeral out, cos I've no parents to... I've got all this to sort out. (232-237)	Sandra
		Yeh, because it was about six months since when I'd lost my Mum, do you know what I mean....so six months later I fell pregnant so.... that gave me the (sighs) so I didn't have no time to do a bereavement, just going to be a good Mum, do you know what I mean, better than my Mum. (273-276)	Sandra
		And again, I didn't have no one to share that one with, only her boys. But then her boys...I didn't worry how I felt, it was those boys, I was going to help... counselling those boys. [] Those boys needed the counselling, don't worry about me (736-738)	Sandra
		Cos I find that ... well, [Cruse volunteer] says it's my strength and my weakness, sort of like a double edged sword, is the fact that she says I'm strong and erm I get on with things (374-376) Erm, I'm blessed in so many ways, erm and I think you've just got to get on with it and I think that was...really where I was concerned that I would get stuck (377-379)	Lorraine
		OK, for me...for me it's been a split between... I mean there is a bit of a split between... looking after yourself and looking after other people or being there for other people. And I suppose I've got, for some reason, I tend to see them as being separate things which I know they're not because obviously if I'm feeling better then I'm better for other people, but I find that's an awkward area for me. So I suppose that's a sort of stuckness, isn't it? (Jenny 554-560)	Jenny

Master Theme 4

Impending Doom	they said he had a cold, nothing to worry about then suddenly it's meningitis, they couldn't revive him and he passed away.(81-83)	Sandra
	I sometimes I wake up, and I think I'm waiting for something, you've got that feeling you're waiting for something and it occurred to me that I'm just waiting to die. (200-202)	Mabel
	I didn't want to get stuck because I know also that you have to grieve because if you leave it locked inside you'll pay for it in some way, it'll come back and bite you somewhere (237-239).	Lorraine
	But, I don't know. I mean, I don't know how I'll feel. It's so difficult to predict how you'll feel. Things that you don't... think are going to get you, do and it is like a knife wound. And then other things, you sort of... I don't know - whether useful – gear yourself up for it more or something to sort of... so that it doesn't hit you as badly, I don't know. But erm, I don't know. (469-473)	Lorraine
	Do you know what I mean, I just really do just get stuck. I think, right who's next. And I find it really hard to get close to people, because I think if you get close to me, you know, something might happen. (300-304)	Sandra
	That's my biggest fear. Do you know what I mean, everyday it's...I say to myself, do you know what I mean, let me live until I'm 18...until he's 18. Because if it's my time to come, please just let me wait until he's 18 so I know he'll be alright (cries). (311-314)	Sandra
	Because everyone I know died so young. Do you know what I mean, in my family. []My Mum was 44, my Dad was 48, do you know what I mean...my sister was thirty.....32. Do you know what I mean, they were all very young. []You know, my boyfriend, 19...I mean, very young. Then the boy, my nephew, you know 6 months old, very young (319-323)	Sandra
	when my Nan and Grandad go I think, Oh my God, what am I going to do then knowing that that's it. I am me and my son, that's it. How am I going to feel, I try not to think about it, thinking of course they're going to go because look they've had their years. It's like 91,92, they've done really well considering my parents and my sister. Done extremely well, and my partner. Will I accept it more because I know they've lived their life and they've... or will I go back down again knowing "oh my God, I'm on my own now. What am I going to do?"	Sandra
	I sometimes I wake up, and I think I'm waiting for something, you've got that feeling you're waiting for something and it occurred to me that I'm just waiting to die. So I can be with my mum... (201-203)	Mabel
	I just want to be with my family. All of my family are dead. (206)	Mabel
	I've got Mum's ashes and Dad's ashes in there, with all my dead dogs ashes all in little boxes, very neat. But what concerns me more than anything else is what happens when I die? Because the thing I wanted more than anything else was for all of our little ashes, dogs included to be put together.	Mabel
	These poor little old people who died, the council go in there, they just chuck all their precious little things away in skips. It's so sad, and I thought God that's what's going to happen to me. And all my precious things, and Mum's are all going to be thrown away. (278-281)	Mabel
	I think they're somewhere, they've got to be somewhere, you can't just have a life and it just vanishes. Can't. And too many people have seen things to make me think that there must be something else. That's the only thing I cling to, that I really will see them again one day. (568-571)	Mabel
	Then you think if it's going to be so wonderful there, why doesn't everyone kill themselves. Do you what I mean, if it's so good, like everyone says it is, then why is everyone here? Why do you bother? I don't know... I don't know.	Mabel
	I had a really strange experience of lying down, and everything spiralling up and away. And she said... she said 'its like you don't want to be here', and that's been a bit how the grief thing is. Like I don't want to... be in this world.	Jenny
	And I suppose, you know, you know when you're doing a party or say.. and you have to be all jolly, just all seems so silly (laughs) Do you know what I mean? You know when things are superficially, I'm not saying all parties are like that, not for a moment, but you know, that sort of – put on a front and... its almost pretending to be something. (911-916)	Jenny
	I think that's more difficult now because you think what's the point, we're all going to die. (918-919)	Jenny
	I've found the whole idea of school a bit harder... because, because some of its just very small little, you know, next exams, results and of course they are important, but... there are more important things... wellbeing. (922-924)	Jenny
	Everybody needs somebody, and if you have somebody... that will help your grieving process and how you deal with life and... And I don't think you become, as you say this thing about being stuck, because you know if you have a moment, thinking about something, you can just pick up the phone or send an email, or go and see someone. I don't think... you'll become too stuck too much. Does that make sense? [] Because sharing something with someone, I don't know.. it's just lights your heart and your feelings, you know – do you remember when... and sharing thoughts and things together. Because I don't believe that's stuck then, that's just helping each other. (959-969)	Sandra
	Yeh, it kills me, because something somewhere was wrong over that. (99)	Mabel
	That's what kills me. That also kills me because on my Doctor's report, he put heartattack. The inquest said lung cancer. She didn't die of lung cancer, she had a bloody heart attack. You don't just drop dead with lung cancer, and that's what also kills me, it kills me. (110-113)	Mabel
	That's what kills me. It eats me up everyday. (121)	Mabel
	Then you think if it's going to be so wonderful there, why doesn't everyone kill themselves. Do you know what I mean, if its so good, like everyone says it is, then why is everyone here? Why do you bother? I don't know... I don't know. (572-574)	Mabel
	And now I just feel...like I'm hanging on the edge of this big dark hole and my fingers...are just my last fragments of sanity and that relentless tormentor called grief is trying to peel my fingers away from the edge of that hole. And I don't where I'll go when my fingers come off. (cries) (191-194)	Mabel
	I sometimes wake up, and I think I'm waiting for something, you've got that feeling you're waiting for something and it occurred to me that I'm just waiting to die.(201-203)	Mabel
	All those things were when I was alive, because I'm not alive anymore. It's just half a life now, if that (289-290)	Mabel
	So now I'm stuck in this terrible place (cries) and I can't get out of it because... there's so many things that I wanted answered that weren't. (143-145)	Mabel
	cos the undertakers came and they put him in a bag and took him downstairs. And I said, is it possible to open the bag because I didn't like it (laughs) (83-85) I just wanted, you know, I just wanted him there not bagged up... sorry. (97)	jenny
	When you go in [labyrinth] you Release, when you're there you Receive, and when you come out you Return. Ok, and I've done this a few times, tried it and I feel ok going in. [] I feel ok when I'm in the middle... and I don't want to come out. And I think that's the sort of...it's like. You sort of withdraw from the real world in a way. (439-446)	jenny
	Even though they're alive, but they're not, do you know what I mean, because I haven't seen them. (250-251)	Sandra
	Even when I'm asleep, dreaming. Do you know what I mean? They're actually talking to me, in my dreams. And I'm, you know, asking... you know and they're still alive, do you know what I mean? They're still alive, they're exactly the same as I remember them. And then I wake up after the dream and I remember everything they've said, and they've done and I think Oh my God, have I just dreamt that? Are they still alive, and then woahhh back again. And I get stuck again. (389-395)	Sandra

Master Theme 4 Cont'd

Loneliness	Oh my God, how did I... you know... why am I here today? Maybe because I'm such a fighter, I don't know but it just keeps spiraling and spiraling. And finally I found happiness, with V, my first..., and then he went. And that was like (sighs) 'here we go again'. Am I meant to be happy, do you know what I mean? Am I meant to be happy? You know, fall in love, have that fairytale we wished for. (668-676)	Sandra
	And I tried hard with her, Pilgrims Hospice, Social services and everyone to get some help, but I couldn't get any. Nobody helped. (10-11) ...Nobody helped. (13)	Mabel
	I kept trying to find somebody to come and sit with her so I could go and start emptying her bungalow (18-20)...But I couldn't find anyone.(22)	Mabel
	It is scary because there's nothing there. There's nobody, I've got no one (197)	Mabel
	All of my family are dead. They're all there, but I'm here on my own (cries). (206-207)	Mabel
	And I had to go there all on my own, and I had to clear her little house. (254).	Mabel
	Then I had to choose her coffin, all on my own. And I had to pick her ashes up, all on my own. And I even had to drive myself to her funeral because there was no one else. (257-259)	Mabel
	Because the thing I wanted more than anything else was for all of our little ashes, dogs included to be put together. But who on earth is going to do that for me? Nobody. (275-277)	Mabel
	I didn't really have any. I sort of declined with friends when I started looking after mum. (658)	Mabel
	So being an only child, you don't sort of, I don't know...you learn to amuse yourself. You do. (667-668)	Mabel
	I've got a wheelbarrow, I just need someone to push it. (794)	Mabel
	Like I don't want to... be in this world. [] So there are times when I've learnt to be ok on my own, but I don't want to go out (419-423)	Jenny
	So we'd only been down here four and a half months when he died, so I didn't know anybody, (128-129)	Lorraine
	when he died I...it was impersonal there and I felt vulnerable and I wanted to be somewhere I felt part of a community	Lorraine
	But... and then at the end of the month I'm going to the National Leader's conference for the Church that I'm with and we went last year. And, it's just that I m...it's sort of...I did this last year but I had [husband]. (342-344)	Lorraine
	And er, I've everything that we... the job sharing we did, I have to do it all now, you know. (391-392)	Lorraine
	Yeah, I know he'd be happy for me, but I'd found somewhere so lovely erm that I can't share it with him and that I find hard. (607-608)	Lorraine
	And my poor M, my little boy. Because I'm...he's the only one...you know...left. (cries) Sorry (257-258)	Sandra
	but again as soon as I fell pregnant he was like... "don't want the responsibility". (270-271)	Sandra
	Even though my Nan and Grandad, bless them they're in their 90s. They're on their way, won't be long. I dread when they've gone, bless them. (323-325)	Sandra
"The same puzzle over and over again": Stagnant	I find next to the grieving process is acceptance, know what I mean... accepting that they've gone. Yeah and I have. I have accepted, know what I mean...that I am on my own now and do you know what I mean, I've accepted that they have gone (429-432)	Sandra
	I did feel alone, yes. Because my sister had a husband then, She was married. [] So she had her support, do you know what I mean...support, she had someone to talk to. I felt, as I say I was on my own at that time, and I felt, yeah very alone, very alone. Yes, when it was like going to say goodbye to her, switching the machines off, I felt very alone then because everyone had a partner, someone to hug. Do you know what I mean? I was just 'hmmm hmmm, I need to get out of here' (724-732)	Sandra
	I hate them dreams, hate them. It's nice because in some respect that they're talking to me, and they're telling me.. do you know what I mean... how's things... like I'm sitting next to you now. Like chatting away, and how you been and that. "How've you been?" 'Yeah we've been fine". Like talking, and then I think... I wake up thinking are they really dead, or are they hiding from me? [] Or are they...where are they? Do you know what I mean like, I sort of think hmmm, why did I just dream about that? And then it just...again, open the puzzle book ..nur eh nur... (398-407)	Sandra
	They played <i>Ave Maria</i> , can you believe which is just about the worst thing. It was played at my father's funeral and then <i>Silent Night</i> which is my mother's favourite. And I started crying and I'm queuing up at the checkout. (424-426)	Mabel
	I do see people that look like my mum. Really, just for a few seconds (cries) you want to call out, cos it looks like them. (434-435) I looked in my rear view mirror, I swear it was my mother sat in the passenger seat in the car behind me. How I didn't have an accident I don't know. Exactly like her, so painful (437-440)	Mabel
	I think it's a continual thing really. I think, I mean what I've tried to do and I continue to try to do is when something comes up, and issue that comes up, try and deal with it and then you get another one coming up. [] Because there's, in a way there's quite mammoth tasks. You know, practically and obviously emotionally (254-259)	Jenny
	I played it two or three times, just played it through. Sat and cried... got over it. Erm, (laughs) it just seems every time you face a hurdle, you get over that hurdle and then there's another one [] Just coming up behind it, you know (580-583)	Lorraine
	I mean I didn't...the wedding anniversary, you know about. His birthday next week, you know about. I didn't expect and didn't realise that the fact that it was a new year and that he died last year would hit – it hadn't occurred to me. It just hadn't occurred to me. And perhaps for some people it never does, I don't know, but for me it was very significant. So that was something that sort of hit me that I wasn't expecting, that was totally out of the blue. (583-589)	Lorraine
	I was fine seeing the football match, but then I saw the referee and that finished me off. Erm, just seeing the referee in his black kit running up and down and that used to be D. It's things like that, things that are particularly special. (615-618)	Lorraine
	constantly. 24- sort of 7 every time I think of a love, or of certain songs that played or anything, a certain smell... um it's sort of silly things like scarring. That if I see someone's got a scarring on a hand, he had a sort of scar on his hand. But things sort of trigger (38-42)	Sandra
	All of the past just went pwoosh, kind of flaming by. I remember you from blah blah blah... and it just reminded of my childhood and I got into depression. Because I thought Oh my God, it just brought everything back. (162-164)	Sandra
	I don't know what to do... I've tried this counseling to help me but it doesn't help, I've done it for two years. I've haven't gone anywhere, I don't feel any better. (199-201)	Mabel
	I just can't move forward, I never feel better, I never have a good day, I feel just as bad now as when she died. (221)	Mabel
	God, how may tears have I cried? I've sort of been in a permanent state of myxomatosis in my eyes. (369)	Mabel
	Yeh, I'd like to do that [painting] as a living really, so I can stay here and not have to go anywhere.(419)	Mabel
	Probably about six months on. I just didn't feel any better and as the time goes on the pain gets worse and they say time heals. It doesn't. (579)	Mabel
	It doesn't heal at all. No. I feel worse now, as I said. I wouldn't have the strength now to do her house [] for her funeral. I've probably got weaker now, it's wearing me down. (582-585)	Mabel
	And when I think about it now, I don't know how I did that because I couldn't do it now. I couldn't have gone now to clear a little house out. [] I don't know how I did it. I don't know how I did it (sighs). (260-263)	Mabel
	So I suppose that's a sort of stuckness, isn't it? [] And you sort of go over the same...some of the same things.	Jenny
	we've stayed put. And I thought that was important because of the schooling and everything and the neighbours, there's a lot going for it here, going for us here. Erm, but somebody said, because I was doing a lot more work in London, 'well why don't you move closer to London?' and I thought 'What a stupid thing to say!' and then I thought well actually that's stupid of me not to consider options as well. So that's another stuckness, isn't it? (595-605)	Jenny
	And this is what... a problem a lot of people like myself as we'll get stuck because we either do the same puzzle over and over again, or be looking for another... you know.. bits of puzzle you know pieces and that's when you get stuck. (374-377)	Sandra

APPENDIX X

Example Interview transcript – ‘Mabel’

Int: Ok, erm, when you're ready, perhaps you could tell me a bit about who we're talking about, who you've lost and how and when she died.

Mabel: OK, it's my Mum and it's um 2 years ago tomorrow and she was killed (cries) as far as I'm concerned, she was killed. She had lung cancer but she was doing ok... as far as you can.

Int: mmm

Mabel: And um, I moved her in here with me on the 6th December because she kept falling over, she... she was having trouble with the walking. So she moved in here with me and um her walking deteriorated very quickly but she was still really bright. And I tried hard with her, the Hospice, Social services and everyone to get some help, but I couldn't get any. Nobody helped.

Int: no space for her?

Mabel: Nobody helped. Then she ended up on oxygen therapy... every hour...and she had to have clexane injections in her stomach that I gave. Nobody helped. Then we had the community nurses visiting, they were helpful to a point of 20 minutes of the day that they came. We were so worried about me clearing Mum's bungalow, cos Mum said 'Oh God, no we must do it now because (cries) it would be too awful for you to do it when I'm gone, when I'm not here. I kept trying to find somebody to come and sit with her so I could go and start emptying her bungalow

Int: mm mm (nods)

Mabel: But I couldn't find anyone. And then they said um, your Mum's doing really well, we're going to send a physiotherapist to help her stand and help her breathing. Brilliant, we were both looking forward to it. The day before that, um social services sent a man out, and I'd converted next door here which was a larder

Int: um mm (Nods)

Mabel: into a lovely little bedroom for her, and they sent this guy out to fit a grab rail on the wall opposite her bed to help her stand. Anyway... (cries)..the physiotherapist turned up, she was late because it was snowing. She came in and she was a Pakistani lady, she didn't look at Mum's notes. She came in and

introduced herself, within about 5 minutes she said to my Mum 'Stand up'. My Mum hadn't stood up for 5 weeks

Int: Were you in the room?

Mabel: Yes, and I thought 'well she must know what she's doing'. Mum grabbed her little grab rail that she'd just had fitted, and she stood up. And she was shaking from head to foot and she said 'Oh I must sit down'. The physiotherapist said 'no stand there a bit longer'. Mum stood there and she was shaking from head to foot, she said 'no I'm gonna sit down' and she sat down on the bed and she looked at me and smiled, and she said she wanted her commode. I always move the commode down next to the bed for her, but the physiotherapist said 'no come on walk up to it' and it was at the end of her bed. So Mum sat on the commode and we stood outside for her privacy and then I heard her say 'Help me' (cries) 'Somebody help me, I feel like I'm gonna pass out, I want me puffa'. She had an inhaler thing (Pause) I walked into the room, Mum was unconscious then on the chair, and I said to the physiotherapist 'Did she have..' cos I handed it to the physio, I said 'Did she take her puffa?'. She said 'Oh I think so', and she's going '[mother's name]... [mother's name]'and I said 'is she breathing?' and she said (shouts) 'no, I don't know' and she started completely panicking.

Int: mmm

Mabel: And I said 'Oh my God' and I grabbed Mum's hand (rubs own hand vigorously and shouts) 'Mum, Mum, Mum' and rubbed it and rubbed it (cries). Nothing. Then all of a sudden her head went back and her hands came out like this (extends hands and arms out above head) and her eyes rolled and I thought she was having a fit, and I said 'she's having a fit'. The physiotherapist said 'has she ever fitted before?', I said 'No'. She wasn't, she was having a heart attack. (cries).

Int: And you think that....

Mabel: And I lifted her off the chair, I said 'Right we've gotta...' because I used to work in a care home, we were trained every six months in CPR

Int: Yeh,

Mabel: And I worked for the police aswell, and I did the police module in first aid. I said 'Right, we've gotta get her on the floor' and I just went completely cold and I lifted her off the chair and I laid her on the floor, I took her teeth out,

I tipped her head back and I started breathing. The physiotherapist, st...started hitting my mother's stomach, I said 'stop it', but she wouldn't stop it, she'd panicked. She's hitting her stomach and of course she pushed all my Mum's Weetabix up that she'd had for her breakfast cos she was quite happy that morning. I couldn't breathe for her anymore because she was being sick (cries) and the ambulance couldn't find us, they went up there miles up the road away from us. And I phoned them again, so then the emergency doctor and the ambulance turned up (pause) and they.. they...couldn't do anything, they tried, they put a needle in her leg (cries) and she died. And I know it was because that woman came, because she wouldn't have died that day, I was the one that looked after her, I knew she wouldn't have died, she was alright that day.

Int: mmm

Mabel: she was quite happy, she'd had her breakfast, she was reading the paper. She wasn't about to die.

Int: Well the... you got the feedback that she was getting better, having a good day.

Mabel: I know, and if she was about to die, then why would you send a physiotherapist ?

Int: Yep,

Mabel: (cries)

Int: And you didn't panic at all, you were...you had to take charge.

Mabel: And at the inquest, [coroner], who was the like the top coroner....I had a solicitor and he was useless, I can't believe it. Because this woman, this physiotherapist, she denied making my mother stand up, cos she knew she shouldn't have done. She denied it, when she said my mother wasn't sick. And I stood up in the court and I said, she was five foot from me, and I could have killed her I could have honestly, I said ' how can you lie like that? Why are you lying?' And the coroner says 'sit down [Mabel] or you'll be excluded from this court', she said 'these questions are for another court'. So she...my solicitor said 'she's actually saying to you, you've got a case, you could sue the NHS for negligence. You know, it was. If they thought my mother was dying, why the hell did they send a physiotherapist (sighs). (8 second pause). So there we are, I haven't got the money to sue the NHS and that's what eats me up, it kills me everyday.

Int: The injustice?

Mabel: Yeh, it kills me, because something somewhere was wrong over that.

Int: Hmm

Mabel: Something was wrong, she was quite happy my Mum that day. She may have died in two or three weeks time

Int: mmmm

Mabel: Bit she wasn't about to die that day, no she wasn't.

Int: Well you listed a few things that sounded.....

Mabel: She was quite happy, she was quite happy eating her Weetabix, reading the paper, got her sandwiches and crisps ready for lunch. She wasn't about to die.

Int: What did the inquest finish with?

Mabel: That's what kills me. That also kills me because on my Doctor's report, he put heartattack. The inquest said lung cancer. She didn't die of lung cancer, she had a bloody heart attack. You don't just drop dead with lung cancer, and that's what also kills me, it kills me. And the..the pathologist was so Greek you could not understand a word he said.

Int: Hmmm

Mabel: And the coroner said 'Did she have a heart attack?'....and he said 'everyone dies of a heart attack'(pause). Maybe they do, but caused it, that's what I wanna know.

Int: Yeh

Mabel: I know what caused my mother's heart attack and it wasn't lung cancer. That's what kills me. It eats me up everyday.

Int: Do you see the cause as the physiotherapist?

Mabel: Yes, it was.

Int: Ok

Mabel: She wouldn't have had a heart attack otherwise, she had a lovely quiet little life, we had...., if you could see we had a quiet perfect little life, a lovely routine, everyday the same thing. We was quite happy.

Int: mmm

Mabel: Quite happy, she'd come in here and sit by the fire. You know she'd have a wash here in the front of the fire and... it was fine. And then this woman turns up and my mother's dead. That's not a coincidence.

Int: And then denies what she did.

Mabel: Then denies what she did, I can't believe that.... Can't believe it, but the police... of course they came because it was sudden death at home. And I sat in there, I used to work for Kent police, my ex-husband's a policeman who's now a solicitor. And I said to the policeman at the time, 'she made Mum stand up'. I've told everyone, the ambulance people, all of those people. [Coroner] refused to call them as witnesses.

Int: Right

Mabel: And my husband said, my ex-husband said, 'make sure they're called as witnesses because you told them minutes after your mother died what happened, and that is the crucial evidence'. She wouldn't call them... No, she didn't call them... (sighs). So now I'm stuck in this terrible place (cries) and I can't get out of it because... there's so many things that I wanted answered that weren't.

Int: Right

Mabel: And I feel she was... stolen from me, she'd been...she was murdered as far as I'm concerned.

Int: Right

Mabel: She was.

Int: But no one's been...

Mabel: No,

Int: prosecuted

Mabel: No... my own GP that also treated my mother. I went to him and I said to him 'I want to complain about this physiotherapist' and he said 'why don't you just move on?' he said 'why do you want to ruin someone's career?' ... How can I ruin someone's career if she wasn't responsible? And then...he wrote to me and said 'I refuse to see you anymore, I feel our relationship has broken down'.

Int: Because you asked that question?

Mabel: Yes...oh how amazing (cries) doesn't all of that make you think, 'hey what's going on here?'

Int: Yeh,

Mabel: Yeh, absolutely

Int: Was the physiotherapist part of his surgery?

Mabel: No... she's part of... the hospice.

Int: Right

Mabel: yes, but he had a lot to do with her coming.

Int: Right

Mabel: So he refused to see me anymore

Int: So I get this real sense that you're alone.

Mabel: Yeh

Int: Your doctor said no, the coroner said no

Mabel: Yes

Int: No one believes you.

Mabel: No, but they all know very well what happened... (sighs). Yeh, they know very well and you've always heard that expression of closing ranks, mustn't that look like it to me. ..Yes.

Int: So, if you're able... to tell me, what were the main feelings that you were left with at that time?

Mabel: I was cheated, I was cheated

Int: Yeh

Mabel: And robbed, (cries) of extra time... with my Mum. I was robbed of it (cries). And they've all lied about it, and I'm not making it up and I don't believe for a moment that I'm kind of imagining things because what I've said to you are the facts. And you as a detached person surely can see my point, that it doesn't seem right, what happened.

Int: No

Mabel: (cries) So as far as I'm concerned, my mother was killed that day and there's absolutely nothing I can do about it.

Int: And those feelings that you had then, do they feel the same now?

Mabel: It's worse now. And now I just feel...like I'm hanging on the edge of this big dark hole and my fingers...are just my last fragments of sanity and that relentless tormentor called grief is trying to peel my fingers away from the edge of that hole. And I don't where I'll go when my fingers come off. (cries)

Int: What you describe there sounds so scary

Mabel: It is scary because there's nothing there. There's nobody, I've got no one. (cries). Just go along, grief and pain keep poking you and prodding at you all the time, trying to lift my fingers off the edge (cries). I don't know what to do... I've tried this counseling to help me but it doesn't help, I've done it for two years.

I've haven't gone anywhere, I don't feel any better. I sometimes I wake up, and I think I'm waiting for something, you've got that feeling you're waiting for something and it occurred to me that I'm just waiting to die.³ So I can be with my mum...

Int: So it's not the sense of waiting for justice to be made, it's waiting for much...

Mabel: I just want to be with my family. All of my family are dead. They're all there, but I'm here on my own (cries). The only thing that keeps me going are this lot (points to dogs). I couldn't leave them, it's not their fault. (cries)

Int: Who else have you lost in your family?

Mabel: My Dad, my cousin who was like my sister. Mum always said... she was only 52 when she died... Mum always said 'I always thought you'd have [cousin] if I went, you'd still have P' but P died and her son died at 14. And I haven't got any other family. My dear beloved Auntie lives in Worcestershire and she's 82 now and Mum's brother lives at C... and er, he's terribly ill now. That's it...that's all the family there were.

Int: Sounds like you've had a lot of grief

Mabel: Yeh...(sighs) Yeh, I've had a lot of grief.

Int: mmm.... And you've mentioned feeling stuck. And we all have different definitions of what stuck feels like - I wonder if you could describe how yours feels?

Mabel: I just can't move forward, I never feel better, I never have a good day, I feel just as bad now as when she died. And the erm, do you mind if I have a cigarette?

Int: (Shakes head)

Mabel leaves room

Mabel: Where was I?

Int: Erm, describing stuck, you never have a good day.

Mabel: No, the erm, they sent someone out from the mental health crisis team about a week after mum... two weeks... something like that, after she died. I didn't like her very much (laughs) and she said to me... she gave me leaflets. Brilliant. Everyone needs a leaflet, don't they? And it said in the leaflets that

³ 18:56

erm 'approximately six weeks after death you will start to feel better'. Six weeks? Where did that come from?

Int: Where does that come from?

Mabel: Yes exactly. Th...they...they are leaflets. And then it said 'typical...typical things you can expect is when you're out you see someone that looks like the bereaved, and when you're this you expect to see them there.. and that...and then another six weeks on you should be feeling this and another six weeks after this you should be feeling that'. Oh that's really helpful, yeh really really good. So I didn't want to see her anymore. She just sat there and basically talked about her French holidays. Brilliant. Yeh

Int: Really?

Mabel: Yeh, Yeh.

Int: Seems like such huge expectations on your shoulders.

Mabel: Six weeks, you're meant to feel better in six weeks. And I was hopeful that I would, because this leaflet..

Int: of course

Mabel:... said I should.

Int: mmm

Mabel: But I didn't. And I did try and do everything everyone said you should do, I did. Yeh, I went out with the dogs, I did this and...the worst thing was I had to do mum's house, because I hadn't done it (cries).

Int: And you had in your ear that she didn't want you to do it when she'd gone.

Mabel: And I had to go there all on my own, and I had to clear her little house and all her precious things are all stacked upstairs, this is only a very small house. But I kept them, and I looked out the window...(cries) and I saw that removal van stood there, and I could see her furniture in there. Then I had to go and choose her coffin, all on my own. And I had to pick her ashes up, all on my own. And I even had to drive myself to her funeral, because there was no one else. And when I think about it now, I don't know how I did that because I couldn't do it now. I couldn't have gone now to clear a little house out.

Int: You found strength from somewhere

Mabel: I don't know how I did it. I don't know how I did it (sighs). But there wasn't anybody, and there aren't any organisations that help you. I went for counseling at the Hospice...pointless. This woman who was very pleasant, very

nice lady, she sat there and she told me exactly what I knew. She said 'I am seeing a woman that is absolutely distraught with grief'. I know that, that's now why I'm here, you know this is just ridiculous. My God, I think I went there four or five times, this is pointless, absolutely pointless. I don't know what I'm looking for, I don't... I know there isn't a magic pill that's going to make me feel better but surely something must.

Int: mmm

Mabel: Something must. So...I've got Mum's ashes and Dad's ashes in there, with all my dead dogs ashes all in little boxes, very neat. But what concerns me more than anything else is what happens when I die? Because the thing I wanted more than anything else was for all of our little ashes, dogs included to be put together. But who on earth is going to do that for me? Nobody. What worries me, is I've seen, you see all these programmes on the television. These poor little old people who died, the council go in there, they just chuck all their precious little things away in skips. It's so sad, and I thought God that's what's going to happen to me. And all my precious things, and Mum's are all going to be thrown away.

Int: And your precious things include people that you loved

Mabel: It's all our family photos, that wouldn't interest anyone else. Like, I've got my Mum's and my Nana's wedding ring, what'll happen to all of those things? And there's photos of Mum, that's Mum and Dad next to you there (points to photo on table)

Int: That's a lovely picture

Mabel: I know, I took that. That was the Kent County Show. They supported me all my life with my horses. I used to teach riding, I used to have a wonderful life.⁴And now I say to my counsellor, all those things were when I was alive, because I'm not alive anymore. It's just half a life now, if that.

Int: I was going to ask you what the differences were two years ago to now. It sounds like you feel... like you don't have a life now.

Mabel: I haven't got a life now. My whole world ended when my Mum died, she was my best friend. She wasn't just my Mum, she was my best friend. We had huge... just such good fun and she was so funny. We had so much fun together,

⁴ 28:50

even if just going down to [location] and buying fish and chips and sitting by the sea and eating them.

Int: So knowing she was going to come back and spend her last few months with you...

Mabel: Yeh but it wasn't, I was robbed. And...the other... I have this massive regret that I didn't give up work sooner. That I hadn't had that summer of quality time with her. Why did I wait til it was too late to give up work? I don't know. (sighs) I don't know why I waited so long, I suppose I didn't believe she was so ill. When we went in there, she'd had breast cancer. She had a mastectomy, sailed through it, absolutely sailed through it at 75. And then she got lung cancer, and the thing was, it was totally unrelated to her breast cancer, it was another primary tumour. It wasn't secondary, how unlucky was that? Chances in a million to do that. When we came out of the hospital and they told her she had lung cancer, Mum said 'Huh' and I said ' Oh well it could be worse' and we laughed, we laughed. And she said how could you possibly say it could be worse, well it could be worse... well it could be... it could be worse. But we laughed, cos it's all you can do. You know, that's how we were, so upbeat and wouldn't let anything get us down. I've always been like that, always looked on the bright side of everything, you know, every cloud and all of that sort of thing.

Int: So this has robbed you of that as well.

Mabel: Yeh

Int: Can't look on the bright side

Mabel: There is no bright side

Int: What about the things that you need to do , like sleeping and eating.

Mabel: I don't sleep.

Int: You don't sleep?

Mabel: I go to bed exhausted because all day I try and keep so busy. I walk for hours with the dogs, and I've got a field I poo pick after the ponies. (sighs) I'm an artist as well, I lose myself sometimes in my pictures, quite happily. I don't get enough commissions really. I don't even advertise now, I used to be quite good. Um, and I go to bed tired, as soon as my head hits the pillow I'm asleep but I guarantee that in an hour and a half I'm wide awake.

Int: Right, are you awake with thoughts?

Mabel: Tormenting me of how I could address with this problem with that physiotherapist. It's just like someone was murdered and they've got away with it.

Int: And I guess she's still practicing?

Mabel: As far as I know, and do you know what? When I worked in the care home, if anything went wrong in the care home, you were suspended, immediately until it was looked into.

Int: Was she not?

Mabel: She wasn't. How... I doubt that she advertised the fact that she made my mother stand up.

Int: Was her version that your mum just stood up?

Mabel: No her version was all she did was made my mother do ankle rotations. She never asked her to stand up, she never stood up.

Int: Wow

Mabel: Absolutely

Int: let alone walked to the commode

Mabel: Yeh

Int: Gosh, that's really different

Mabel: Yes isn't it. Isn't it just... God

Int: How does your experience over the last two years... how does that compare with, well either your previous experience of grief or your expectations of grief?

Mabel: (sighs) My father died in hospital, I was with him

Int: mmm

Mabel: And he died, and we knew he was going to die. It was his third heart attack

Int: Right

Mabel: He'd done very well, you know he's always rallied but.. he died and we, WE grieved him.

Int: Right

Mabel: But we had each other.

Int: You and your mum?

Mabel: (nods) and we came through it quite quickly and quite well. And we could speak happily of him.

Int: It's that you're alone... now

Mabel: I'm alone, but she didn't just die. She didn't just die, I was prepared for her to die. Of course she was going to die, but not that day, not like that. No. And for my GP to refuse to see me anymore (laughs) that was wonderful, absolutely marvelous support. (blows nose) I'm a very snotty person

Int: Comes with the tears

Mabel: I know. God, how many tears have I cried? I've sort of been in a permanent state of myxomatosis in my eyes.

Int: When you're out walking?

Mabel: No, I'm good when I walking, I'm good.

Int: ok

Mabel: Yeh, I'm really good, I don't think about anything. It's the only time I don't think about anything, just walk and my mind is completely empty apart from my walk.

Int: Wow

Mabel: It's really wonderful.

Int: That is...

Mabel: But I walk, I really walk. We walk for miles.

Int: Yeh, you don't want to come home?

Mabel: No, and I walk all across the marshes here with... it's just marvelous, absolutely marvelous. It doesn't matter what the weather is, I walk and it's wonderful because my poor little mind actually has a rest.

Int: Yeh

Mabel: It really does, and it's amazing how I... you think when you walk you might think, but I don't. I don't think. I just....

(a lantern falls off the fireplace)

Mabel: Yep, well that's possibly mum, (laughs) that's possibly mum. I don't think when I walk. I just walk and er can I show you...I've got a couple of pictures I've done.

Int: Absolutely, please do.

Mabel: Yep...(leaves room and re-enters with a sketch pad) Just done these, I've contacted the local vets and things. But I've just done these as examples but it's animals that I do. (*shows a pastel drawing of an Alsatian and a Husky*)

Int: Wow

Mabel: Yeh?

Int: That's beautiful

Mabel: And I don't think when I draw, either...

Int: Aww, a husky. That is beautiful, and so it's the same as walking for you, drawing?

Mabel: Yep, I don't....my mind is just on that.

Int: And do you do this less in the last two years, have you found? Less.

Mabel: Yes, less

Int: Less space in your head

Mabel: I used to do quite a lot, commissions you know?

Int: Mmm

Mabel: I've done erm four over the last two years.

Int: mmm

Mabel: I'd like to do more, but I don't know if I can. It really takes a lot to get.. but once I get myself up to do it

Int: Mmm

Mabel: Then I'll do it,

Int: Yeh

Mabel: But I...

Int: What do you use? Pastel

Mabel: Pastels, yeh.

Int: Absolutely beautiful.

Mabel: Yeh, I'd like to do that as a living really, so I can stay here and not have to go anywhere. I find it very hard going shopping. The worst time was erm Christmas, in Sainsburys in [location].

Int: Right

Mabel: And that's only a little Sainsburys and I try to go there because it's small. They played *Ave Maria*, can you believe which is just about the worst thing. It was played at my father's funeral and then *Silent Night* which is my mother's favourite. And I started crying and I'm queuing up at the checkout. I was doing anything, my fingernails were nearly cutting through my skin trying not to cry. I was looking everywhere

Int: mmm

Mabel: I was reading labels on the tins and doing anything I could, and I started crying and I had to just abandon my shopping and leave, it was so

embarrassing. I could have died, just awful. I had to come home, with no shopping. And this happens quite a lot... no I just... and I do see people that look like my mum. Really, just for a few seconds (cries) you want to call out, cos it looks like them.

Int: mmm, til they turn around.

Mabel: Until they turn round. And I was driving home the other day and I looked in my rear view mirror, I swear it was my mother sat in the passenger seat in the car behind me. How I didn't have an accident I don't know. Exactly like her, so painful [8 second pause]. Then I went to, went to a medium.

Int: ok

Mabel: But you do, you do, you do anything.

Int: To try and get in touch with your mother?

Mabel: No, it's not particularly getting in touch, it was just knowing that she's ok. That's all I wanted.

Int: Yeh

Mabel: Want to have a conversat....Just wanted to know if she was ok. And with her family, with her mum and dad.

Int: mmm

Mabel: And she was ever so, ever so good I have to say. She didn't tell me anything ridiculous, said... some of the things she said were quite incredible. Yes, she spoke about my uncle who was a steam engine driver in the old days.

Int: mmm

Mabel: And he had an only daughter and that's my dear aunty in Worcester. How could she know that?

Int: mmm?

Mabel: And then she said 'you draw animals don't you?' How could she know that? And then she described my father to a tee who was standing next to her she said. And then she said your mother's standing next to you, now she didn't know me. She said 'I can hear someone calling out a name' She said 'it sounds like [mabel]' I said 'could it be [mabel]?' She said 'Yes'

Int: And she didn't know your name?

Mabel: No... What are the chances of that, of a guess? Of J.. or J...? That's really spooky, no she was wonderful.

Int: How were you feeling in there?

Mabel: I felt good at the time because I thought, actually maybe she is ok, but what was weird, before Mum died we spoke about erm... I said to her 'If anything happens to you, will you let me know you're ok when you get there?'

Int: Yeh

Mabel: She said 'Yeh'. When she died I had erm three people from the village.

⁵Everyone comes round don't they the day after, they always do. You never see them again

Int: then nothing...

Mabel: but they always turn up. Three people from the village were sat here, three women...my mother's alarm clock went off. This was twenty to nine at night

Int: mmm

Mabel: She never set her alarm clock, if she had set her alarm clock it wouldn't have...(shouts to dogs) *What you eating?* It wouldn't have gone off at twenty to nine at night.

Int: no?

Mabel: It just started ringing, oh it was really weird.

Int: Did you take comfort from it?

Mabel: (sighs) I don't know, I don't know. That was so weird, why would that start ringing at twenty to nine at night.

Int: Yeh

Mabel: It would have had to be set for twenty to nine the day before

Int: mmm

Mabel: She wouldn't have set it then, no. She never set her alarm. Oh I don't know.

Int: mmm... So things like, like that lamp falling off

Mabel: Yeh, that's quite amazing really (laughs), really.

Int: Do you get the sense that she's around?

Mabel: I don't know, I mean...it didn't break, the hook's come off.

Int: Wow,

Mabel: When I moved here... four years ago... four years ago this was pretty derelict. I've kind of.. revived it and erm, there weren't any carpets so I had it all

⁵ 43:22

carpeted and upstairs and on the third night, I heard footsteps across the ceiling here. But the dogs were all barking at the ceiling, so I thought well clearly I...

Int: You're not alone hearing it

Mabel: No, I'm not no. I'm not imagining this because the dogs are so I thought well something might have bounced off, but this was footsteps on floorboards, well there aren't any because I've had it carpeted. Twenty to seven every night, footsteps on the floorboards, dogs barking, going berserk. At the end of the week, I was a nervous wreck and the dogs never ever used to sleep upstairs but I took them all up to bed, so we're all in bed and all of a sudden they've all got up and their hair has stood up down their back. Four pairs of dog eyes have followed something round the room, all growling. I couldn't see anything but dogs are...they can see things. And I thought, right that's ridiculous so I said to mum 'I can't put up with this, I've got to stay'. Anyway, I stayed at Mum's for a week with the dogs, I contacted the local vicar who, held Mum's service. I know her because I was a community warden with Kent police and so was she.

Int: mmm

Mabel: S...B. She said, 'I know you wouldn't imagine things J'. I said 'no I'm not, come round' So she came round, she said 'no it doesn't feel quite right' and I had no idea that the Church of England do exorcisms. But they're big on it, so I thought, well they wouldn't do that if they didn't believe... would they?

Int: No, no

Mabel: They wouldn't.

Int: No, not at all.

Mabel: So anyway I had the vicar of A... and the vicar of T... came to the house, all their robes, this, water, prayers and we went round all the rooms of the house and I was absolutely freaking out. My mother said at the time 'Ah, I don't know how you can do that'. I said 'No, I got to do it cos I want to live there.' So they've gone round, blessed all the rooms and they were sat in the kitchen having a cup of tea, like you do with vicars. It was about half past four on an October afternoon so it was fairly dark

Int: mmm

Mabel: And I said to them 'how will I know it's gone?' And he said 'Oh you'll know'. All the lights went out, two minutes later they came back on. And I said,

'I take it it's gone then?' He said 'Well I can promise you'...shaking hands.... 'that that's never happened before' (laughs)

Int: Wow,

Mabel: Yeh

Int: And anymore footprints?

Mabel: No.

Int: Well I never

Mabel: Nothing. From that day on. Nothing at all, but and I know you probably think I'm completely mad but I really don't think I am... There are things called orbs

Int: ok

Mabel: And I do see them here, there's something back here but I'm quite comforted by it to be honest. There's...I had some builders in to redo all the plaster there in front of that wall and it was only er, four months ago and I walked back in, I hadn't been smoking or anything, and as I walked in there was this cork screw of sss...looked like smoke in front, like it was looking at the wall. And I said to myself, out loud 'I saw that, (shouts) I saw that'. I said to the dogs 'I saw that' because I thought I'm completely losing it, but I saw it.

Int: mmm

Mabel: There was nothing... and the dogs now see, which we do see... these little... you get this little black thing rush to and fro every now and again and the dogs go 'Oooh'. There's nothing really there but they see this little black shadow flit.

Int: Which you see as well?

Mabel: I see it, yeh, flits around. So I think its probably...but then I can take comfort from that because I think... so many people have seen things, so many reliable people have seen things and witnessed things. It makes you think there must be something else.

Int: mmm

Mabel: That's the only thing I can take comfort from.

Int: Yeh

Mabel: I don't think it can be... you know I just think... where are my mum and dad? They can't just vanish, they've got to be somewhere.

Mabel: They can't just disappear, they can't. They've got to be somewhere.

Int: And you think they're here?

Mabel: No, I don't particularly think they're here, but I think they're somewhere.

Int: Somewhere...

Mabel: I think they're somewhere, they've got to be somewhere, you can't just have a life and it just vanishes. Can't. And too many people have seen things to make me think that there must be something else. That's the only thing I cling to, that I really will see them again one day. (Pause)

Int: That's a comforting thought

Mabel: Then you think if it's going to be so wonderful there, why doesn't everyone kill themselves. Do you know what I mean, if its so good, like everyone says it is, then why is everyone here? Why do you bother? I don't know... I don't know.

Int: When did you get the sense that you'd moved from grieving that everyone else would understand to feeling stuck, like a different place, apart from the six weeks on the leaflet.

Mabel: I don't know, probably about six months on. I just didn't feel any better and as the time goes on the pain gets worse and they say time heals. It doesn't

Int: It doesn't, you're feeling worse.

Mabel: It doesn't heal at all. No. I feel worse now, as I said. I wouldn't have the strength now to do her house..

Int: mmm

Mabel: ... or her funeral. I've probably got weaker now, it's wearing me down.

Int: And have you had any family members, I guess not, but, friends responding to you in this two years?

Mabel: No... people avoid you when you start crying, they can't cope with it. I found that, all the people like I said, you know that turned up after Mum died 'Oh anything you want J, just let us know'. You phone up and suddenly they're busy. I never phone again.

Int: And so after the crisis team didn't go well

Mabel: (Laughs)

Int: and the counselling with the hospice, and I guess you're with...is it KCA at the Live it Well, what led you to Cruse?

Mabel: KCA.

Int: Ok

Mabel: Because she doesn't know what to do next. Sadly the counsellor that I did bond with left KCA and she went somewhere else. And I thought the world of her, she was a real good egg.

Int: And did you start to feel any better?

Mabel: I looked forward to seeing her.

Int: ok, that's important.

Mabel: I did, yeh I looked forward to my Thursday to see [counsellor], I really did. Because we didn't always talk about Mum. She just talked to me.

Int: Yeh

Mabel: She was so nice and she was my kind of woman.

Int: mmm

Mabel: My sort of age, um, country type background like me, knew what I was talking... where I was coming from with the dogs and the horses and everything. Really, really liked her

Int: Yeh

Mabel: And, then the lady I've got now, [counsellor], she's the one that suggested you. She's ok, but she's not my kind of person, do you know what I mean? She's a very nice person, but she's not kind of person. You know she wouldn't drop in an F-word or anything (laughs) but [counsellor] would, you know she was my kind of person. Yeh,

Int: You had a real connection

Mabel: Absolutely, oh yeh, and she did...she prepared me well for her leaving.

Int: Yep

Mabel: You know, she said 'I'm going to... it's three weeks now and I'm going to leave. So it wasn't...cos she said 'this is going to be another loss for you'.

Int: So she was good

Mabel: But no, it was good, I was ready so that's fine, that's fine. And I value having known her.

Int: Yeh, but this counsellor at the moment thinks she's done all she can for you really? Wants you to come to Cruse.

Mabel: Yeh, she's at a loss, really, she is.

Int: Yep, ok

Mabel: Because my...um...do you want... I wonder if I've got it... I've got a letter about my... these scores and charts and...I just think.

Int: Ok

Mabel: You know, you've got a fifty minute counselling session, twenty of which are spent filling out this multiple choice bloody questions every time.

Int: Right

Mabel: How you feel? What would you do if this happened, same questions every week. And she said 'well we have to do it because we have to chart you on this chart for anxiety, depression etc. (sighs, then laughs) I would have thought it was much better just to say to someone, 'how do you feel today?'

Int: Right

Mabel: Rather than a chart, you know?

Int: ok, so is that what you hope from your relationship with Cruse? That you can have a....

Mabel: I don't know. I've got no expectations whatsoever.

Int: Ok

Mabel: I have an open mind because I just seem to have been shunted from one person to the next

Int: yeh, sounds like it

Mabel: cos no one doesn't really know how to handle it

Int: Yeh

Mabel: I don't know. I feel sorry for anyone that's got to come to talk to me, I do. You know, that's why people don't come and talk to me. Who the hell wants to talk to someone that's crying? No one. It's depressing isn't it, really. Sure people have got better things to do, and I used to have. But I like to think.. when I was ok if anyone had been in this state, I would have spent, I would have given them some of my time.

Int: mmm, so have you lost friends over this?

Mabel: I didn't really have any. I sort of declined with friends when I started looking after mum. I've never been a people person, I've always been an animal person.

Int: Yeh

Mabel: And erm, I had a very very good friend that, it turned out that she, this sounds petty when I say it really... but anyway she was using me because she

wanted to have a horse, she wanted to absorb all my knowledge, she wanted me to help her find the horse for her to buy, which I did do. Then when she got all of that, she then didn't need me anymore, so there we are. So my mother never had many friends, nor did my dad actually. So being an only child, you don't sort of, I don't know... you learn to amuse yourself. You do.

Int: Yeh, and the family a tight one.

Mabel: Yes, and I've always been happy with my lot. I've been happy, I've always had horses that I always rode, I'm a qualified riding instructor, I've had a great life and I had a happy marriage for ten years. I still, still question whether I should have left him, but I did leave him.

Int: When was that?

Mabel: erm, it was ten years ago I suppose, yeh. Shouldn't have left as far as financial concerns cos now he's a solicitor for God's sake.

Int: Right

Mabel: (laughs) Oh what an idiot! Mum used to say that, 'shouldn't have left J'. I said 'I know'. (laughs)

Int: What made you leave? Something must have...

Mabel: No, he was just an arsehole really, (laughs) he really was.

Int: Ah,

Mabel: Well when we met, I've always smoked, I've always had dogs. And when we met, 'oh no I don't mind smoking, don't mind dogs. Love dogs, used to have a dog when I was a boy'. Anyway, soon as we got married, hate smoking, hate dogs. It was just, you know, an on-going battle basically and the absolute crux of it was erm, he was doing this open university degree in law, and he had an option of going to Sterling or Brighton. Well he chose Sterling which I thought was a bit strange at the time, then a letter came through the door and I have to say it was an open envelope so naturally (laughs) you have a look don't you?

Int: Ok

Mabel: Course you do, you have a look don't you (laughs). So I had a look, and it was from this woman called [name] with a cheque for her part for the fees for Sterling. And it said, this little covering note... 'Oh I'm sorry to hear of all your problems at home [ex-husband], as you know I'm always here for you.' (laughs) Red mist, red mist descended at the time, so sadly her name was on the cheque. So with my policing abilities I've looked up in the phonebook and then found it,

phoned her up, told her just about what black is white and carried on making it absolutely clear how I felt, but he still went to Sterling and as things progressively broke down between us and I left, guess who he's with now? Helen!

Int: Right

Mabel: Yes, how surprising. Psychic abilities I think. Yeh, I knew

Int: Very accurate abilities, it turns out. Mmm

Mabel: Oh, I knew. But the best of it... we're still kind of sort of friends, you know we do speak and... I went to his house, our marital home for some reason or another and his computer was on and his screen saver was clearly this Helen and I looked at it and said 'Don't tell me that's [name]'. And he immediately bristled and said 'well looks aren't everything' and I said 'clearly'. (laughs) God, pig ugly or what? Oh my God, ah, best of luck [ex-husband] I'm just glad that she's actually ugly. So he didn't go for someone that looked better than me. (laughs) That gave me a great deal of comfort, that really did.

Int: Ah, good.

Mabel: God, she's ugly! God Almighty. So you know, best of luck, carry on.

Int: Right

Mabel: Yes, so now you know my life story pretty much, yes no [ex-husband] in fact was very good about Mum's funeral because I couldn't afford what I wanted for her and he did pay the difference.

Int: Oh that's kind, yep

Very kind, he didn't have to.

Int: So you gave her the funeral you needed to really.

Mabel: Yes, because the basic bog standard funeral that I could afford was this hideous, black coffin. It looked like something off a hell's angel's motorbike, it was awful.

Int: Oh

Mabel: I don't think it was probably black, but it looked black in this catalogue that you have to look at. Oh I said 'I cannot put my mother in that' and he said 'well which one would you like?' I said 'that one'. It wasn't anything expensive, but it was a nice sort of walnut colour and then of course it came to the urn. The urns go up to about £400 (sighs). The only one I could afford was, it was a discounted one because it was slightly damaged, it was a little wooden box,

which actually wasn't unpleasant, so I sort of settled for this little wooden box thing. But I said to the funeral director, 'whatever happens, I want to know at every stage of everything, where my mother is because...she went from here she did not go to the undertakers because there had to be a post-mortem.

Int: yeh

Mabel: And I wanted to know, exactly when she would be at the undertakers, where she wanted to be, where I knew she wanted to be where my Dad went. So I phoned the undertakers on several occasions, and 'no, she hasn't arrived yet'. And I said please, let me know. But they didn't. It was nearly two weeks and I phoned up and said 'is my mother...' 'Yes, she's been with us for three days'.

Int: You should know where she is

Mabel: I said 'You didn't tell me, you promised you'd tell me'. I went beserk. So [ex-husband], being a solicitor has dealings with the undertakers...he phoned them and he said how distressed I was so the Managing Director of Woods phoned me and said 'I am most terribly sorry, that we failed to let you know where your mother was. What can we do to make amends?' And I thought, right, I know exactly what you can do, well I'll tell you what you can do, this beautiful metal casket that's in antique blue with silver roses embossed on it which was £350 odd. I said 'you can let me have that for my mother'. 'Of course', he said. And I came home, and I said out loud, well mum you're gonna be proud of me (Laughs) because I've got you exactly what I wanted you in that I didn't think I could possibly afford.

Int: Mmm, wonderful.

Mabel: So I got it for her. Yes. I mean I could have said 'right, I actually want six black horses and an oak coffin' (Laughs)

Int: mmm, how much...

Mabel: which would have been about £15,000 so I think he got off quite lightly really, I do. Yes, and Mum said all she ever wanted was to be with me, but like I said to you that bothers me a lot that. I had a funeral plan sent to me by Woods so I could look at it, and there's all these, you know, that I could pay into so that I can actually have everything I want, I can't afford it. £60 a month, can't afford it. So what I thought of doing, got seven acres out here, I know I rent this but I thought right, I'll hire a JCB and dig a sodding great hole and then all the

precious things – our jewellery, our photos and everything I don't want the council people to get their hands on. I could bury it. And then I just have..cos this will never be built on here, never cos it's the marsh. The water table levels, you wouldn't build on there. That would all be safe.

Int: Oh I see, you're expecting the...them to come in and hunt down what they collect for money?

Mabel: No, no what I'm expecting is when I die is just anybody's going to come in here and just clear the house. And I just want to make sure my precious things are buried, not expensive, I'm not talking about monetary – precious photos and things that people just chuck on a fire or in a skip that I don't want chucked on a skip

Int: mmm

Mabel: I'd rather have them all buried together together, then I thought right ok, once I've done that I could then scatter mum and Dad's ashes out there so if I was very lucky, somebody would scatter my ashes out there as well.

Int: Yeh

Mabel: And that's all I'd want. So that's the kind of plan

Int: Yeh

Mabel: That's the plan (sighs) I've got so many bloody animals, you know I've got piles of boxes with animals ashes in. I've even got a goat in the dresser (laughs)

Int: Right

Mabel: God,

Int: That you've had...

Mabel: That have been cremated, yes, they've all been cremated at great expense. They've all been cremated and I've always had them cremated because I always think if you move you leave them behind if they're buried in the garden, and I couldn't bear to leave them behind. So they're all piled up

Int: They're with you

Mabel: Yeh, and the plan was to put all of us together, need a wheelbarrow to take us lot up the field there's so many. You would.

Int: You need to start looking for someone with a wheelbarrow.

Mabel: I've got a wheelbarrow, I just need someone to push it. Huh. So there we are.